

# **A THEMATIC EXPLORATION OF CHRONIC PAIN AS DESCRIBED BY PATIENTS**

**Dr ANNE ELIZABETH SUMNER**

MASTERS RESEARCH REPORT  
2005

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# **A THEMATIC EXPLORATION OF CHRONIC PAIN AS DESCRIBED BY PATIENTS**

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Dr ANNE ELIZABETH SUMNER

Research report submitted in partial fulfillment of the  
requirements for a Masters in Family Medicine,  
at the University of Cape Town

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<b>ABSTRACT</b>
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**A THEMATIC EXPLORATION OF CHRONIC PAIN  
AS DESCRIBED BY PATIENTS**

This study explores the experience of people suffering from chronic pain post surgical interventions. Cases are selected from those patients currently attending a pain clinic. By means of five in-depth, unstructured interviews this research seeks to understand how these patients view their pain. Recurrent themes arising emanating from these interviews are identified and then examined. These include: the breakdown in the doctor-patient relationship, and the all pervasive nature and effect of pain on the lives of those suffering from chronic pain. This research recommends that doctors should begin to examine the part they may play in the aetiology of chronic pain. A practical aspect of this might be the rotation of student doctors through chronic pain clinics.

\*\*\*\*\*

KEY WORDS: Chronic pain, Patient perspective, Themes.

\*\*\*\*\*

I certify that the report is my own and all references and quotations have been properly identified,

Signed:

Dr ANNE E SUMNER

<b>DEDICATION</b>
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*My Father*

**Michael Lloyd Sumner**

*1938 – 2001*

\*\*\*\*\*

This work is dedicated to my father who suffered such terrible pain and died during the process of completing this research.

\*\*\*\*\*

## ACKNOWLEDGEMENTS

In the process that spanned the initial conception of this research endeavour and its final documentation, there have been many people who, in different and special ways, have given me much in the way of advice, support, encouragement and understanding. The following list is therefore incomplete, but is written in sincere acknowledgement of my indebtedness to them all.

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- Janine Nielsen who worked so tirelessly in assisting me collate the initial transcripts.

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## Chapter 1: INTRODUCTION

Much of Western biomedicine is based on classical Newtonian science, which is inherently reductionist, and mechanistic; striving to comprehend reality by dividing the whole into increasingly smaller fragments. By contrast, the field of Quantum Mechanics speaks of reality as a probability function, and maintains that human consciousness is a vital factor in converting that probability into the actuality of existence. The difference between these two approaches provides a helpful lens through which the experience of chronic pain may be observed, understood and theorised. Ultimately the focus of this lens begins and ends at the human being's experience of their pain.

Instead of differentiating and even fragmenting the experience of chronic pain into one of physiological versus psychological aetiology, originating in the mind or body or soul, being real or unreal –this research begins with the person. From this perspective, the sufferer experiences their pain as a whole and unified experience, encompassing their physical, psychological and spiritual being. From the level of the individual this experience spreads out to involve family, friends and co-workers. Chronic pain is hence best understood as a complex network of interrelations. Both the systems theoretical model and psycho-neuroimmunology go some way to depict this reality.

By way of pre-empting much of what will follow in the review of literature, it should be clear at this point that physical pain comes in two varieties: acute and chronic. Acute pain can occur during transient illnesses or after an injury or surgery and goes away once the condition clears up or wound heals. In acute pain, pain-specific nerves respond to noxious stimulation or injury by releasing chemicals that transmit pain signals to the spinal column and brain. This type of pain can be treated effectively with short-term use of opioids or other pain-relievers, which generally pose a minuscule risk of addiction.

However in contrast chronic pain may be caused by nerve damage, chronic diseases such as cancer and arthritis, and degenerative conditions such as spinal cord injury. While chronic pain is complex and not well understood, research suggests that prolonged disease states or tissue injury may sensitize certain nerves in pain-signalling pathways. As a result, these nerves may continue sending pain signals to the brain even when the pain-causing condition has been resolved.

Because little is known about this phenomenon, chronic pain is a difficult-to-treat, persistent condition that often requires long-term use of medications (<http://www.ninds.nih.gov>).

## 1.1. BACKGROUND TO THE STUDY

My own interest in chronic pain began through a family member, MJ, who has suffered for over a decade with severe back pain and has sought help from most varieties of health care professionals; general practitioners, orthopaedic surgeons, neurologists, physiotherapists, chiropractors, podiatrists, and on three continents: Africa, North America and Europe.

His fascinating story unfolds against the well-known backdrop of disillusionment, stemming from multiple negative findings on special investigations and sceptical attitudes from doctors. In five years of pain he had known only eight months of consistent relief. This was following intra-articular injections comprising local anaesthetic and a sclerosing agent. These had to be stopped after he left England as the doctor declined his request to disclose exact details of the active ingredients contained in the injections.

He then tells of a time when he finally realised that no one in the world was going to be able to cure his pain. At this crossroads seeing no other possibility he resolved to fix his own back. His partner has been almost visionary in her determination that cure was indeed possible. He resolved then to gather bits of information from every possible source and synthesize these into his own homemade remedy.

Following advice to change his diet to include more protein his vegetarian habits were dropped. Exercise practises were also changed. He stopped running and rowing and took up cycling and swimming. It was at this point that he consulted a neurologist for the single meeting, which he believes to have been the most useful consultation during the entire course of his pain. After a negative magnetic resonance scan she told him that no cause was going to be found for his pain. However she assured him that she would focus on his symptoms. This perspective, of focusing on his symptoms rather than the cause, symbolised a major paradigm shift for MJ. She then started him on a tricyclic anti-depressant, at a dose used for chronic pain.

This neurologist gave M.J. hope that relief was possible at a time when he was open to hearing. His symptoms became more bearable. His own management strategy was well on the way to being developed. This would include short courses of high dose analgesics at a hint of return of pain, as well as massage, hot baths, TEN.s machine application and continued exercise despite pain. His maintenance strategies include back stretching exercises and adequate sleep. His partner remained optimistic in his periods of exacerbation refocussing on how far he had come.

Today, apart from the occasional twinge, he is pain free. His explanation is that he has; "finally learnt to live with [his] back", and believes that he will soon no longer suffer pain at all.

MJ's story has interested me in the problem of chronic pain, which through my experience at the pain clinic I begin to see as representing the shadow of modern medicine, our shortcomings and even at times our failures. It has been suggested that chronic pain is an iatrogenic phenomenon (presentation by Dr S. Bowman at Valkenburg Hospital, 1997).

Returning to MJ's story, what changed to make such a difference in his experience of pain? Arising from this, further questions include:

1. Is the improvement in pain symptom about shifting from external to internal locus of control?
2. If so, what *factors* trigger the shift?
3. Can we as health care providers facilitate this process in our patients?

## **1.2. AIM**

To explore the experiences of people suffering chronic pain of non-malignant origin.

## **1.3. OBJECTIVES**

To look at themes that arise when patients talk about their experience of chronic pain.

## **1.4. OUTLINE OF REPORT STRUCTURE**

Following on from this introduction, a review of the relevant literature is presented in *Chapter Two*. Theories relating to the various physical and psychological aetiologies of pain are laid out. Thereafter, *Chapter Three* presents the methodology underpinning this research. This done, *Chapter Four* moves on to present the findings of this research, especially as these relates to themes touched on by the patients interviewed. The report concludes with *Chapter Five* which containing discussion and conclusion of the findings. Included here is an examination of the weaknesses of this report and a section on potential research avenues opened up by the findings noted. A bibliography appears at the end of this report.



## Chapter 2 – LITERATURE REVIEW

The "real world" is a construct, and some of the peculiarities of scientific thought become more intelligible when this fact is recognized. Using this notion of a social construct, Einstein is reported to have told Heisenberg that it is nonsense to found a theory on observable facts alone, since, in reality, the very opposite happens. The construct of theory enables us to observe only what it permits. For science the implications were clear: observations and levels of explanation were only as good as their underpinning theories permitted.

In the light of the above, it becomes clearer that, despite much having been written in an attempt to understand the nature of pain, much still exists that theories fail to explain. The various theories presented here provide a glimpse of the complex interrelations of biology, psychology and social milieu that cause and influence chronic pain.

The literature review begins with the traditional theories, originating in the 17th century, and looking at pain from separate biomedical and psychological perspectives. Thereafter the more integrated psycho-physiological theory is described, effectively linking earlier theories of the body and the psyche. A study on learning theory as it relates to pain is then reviewed, and an examination of complementary or alternative approaches to pain concludes the chapter.

### 2.1 BIOMEDICAL THEORY

#### 2.1.1 THEORIES RELATING TO PAIN RECEPTORS

##### 2.1.1.a Specificity Theory 1600's - 1800's

Specificity or traditional theory forms the basis of thinking for most neurophysiology, neurology and neurosurgery, and was the model taught to me as an undergraduate medical student. It predicts that identifiable parts of the brain will reliably detect, transmit, and deliver *specific* fractions of sensation, as illustrated below: -



The originator of Specificity Theory was probably Descartes who in 1664 conceived of the pain system as a straight through channel from the skin to the brain.

Descartes' theory changed little until the nineteenth century when sensory physiologists attempted to account for the different qualities of sensation. Muller in 1842 stated that the brain receives information about external objects only by way of the sensory nerves. Activity in nerves, then, represented coded or symbolic data concerning the stimulus object. Muller recognized only the five classical senses – seeing, hearing, taste, smell and touch.

Between 1894 and 1895, a physicist, Max von Frey, proposed a theory of cutaneous senses, which forms the basis of contemporary specificity theory. Von Frey believed that the skin comprises a mosaic of four types of sensory spots: touch, cold, warmth, and pain. From this he postulated that each type of cutaneous sensation had its own specific nerve ending; those for pain being free nerve-endings. He deduced this by simply noting that free nerve endings are the most commonly found receptors and that pain spots are found almost everywhere on the body. Ingenious experiments were later carried out to show that there is a one-to-one relationship between receptor type, fibre size, and quality of experience.

This work was later reviewed by Bishop (1946); Rose and Mountcastle (1959); and Sinclair (1982.) Since fibre diameter is thought to be modality specific, the specificity theorists speak of A-delta-pain fibre pain and C-fibre pain, and of touch fibres and cold fibres - as though each fibre group had a straight-through transmission path to a specific brain centre.

Finally a pain route in the spinal cord was sought. Using studies and operations on animals and humans, it was concluded that the anterolateral quadrant of the spinal cord, called the spinothalamic tract, is the major 'pain pathway'.

In 1920, Head proposed that the central pain centre is situated in the thalamus because cortical lesions or excisions rarely abolish pain, but rather tend to make it worse. Thus the thalamus is believed by some to be the 'pain centre' with the cortex exerting some inhibitory control over it.

### 2.1.1.b Pattern Theory

Goldscheider was the first to propose that stimulus intensity *and* central summation are the critical determinants of pain, not the one-to-one relationship between pain perception and intensity of the stimulus, which had been assumed earlier.

## 2.1.2 THEORIES RELATING TO SEGMENTAL MECHANISMS

### 2.1.2.a Gate-Control Theory 1965

Melzack and Wall first proposed the existence of a specific pain modulatory system in 1965 in the Gate Control theory of pain. This theory was to destroy the idea that pain is a simple sensation caused by a direct transmission line to a pain centre. Essentially two types of peripheral nerve fibre were known to be the most common centrally projecting cells signalling injury. These are the small diameter (S) fibre, which are the myelinated A-delta fibres, and un-myelinated C fibres, and large diameter (I) low threshold myelinated peripheral nerve fibres. These cells deliver impulses, directly and indirectly, to the transmission cells in the spinal cord (T), which transmit to local reflex circuits and to the brain. Generally all synaptic regions contain both inhibitory and excitatory mechanisms, which control transmission depending on the balance of their activity.

It has long been known that powerful influences descend from the brain and modulate spinal reflexes. In 1954, Hagbarth and Kerr showed that these descending effects also changed sensory messages travelling from the cord to the brain. In 1964 Taub moved on to show that local stimulation in the midbrain and medulla inhibits the firing of T cells. Later in 1967, Wall found evidence of a powerful, steady inhibition flowing continually from the brainstem to T cells. It was therefore reasonable to include a descending influence on the inhibitory inter-neurons.

Finally, in 1996, Melzack and Wall, putting the picture together, assumed that ascending messages to the brain could influence the descending controls, thus completing a loop from spinal cord to brain and back to spinal cord. They presented this as the Gate Control Theory.

## 2.1.3 CONTEMPORARY THEORY 1996

### 2.1.3.a Nociceptors

Thus far this section has presented the most historically significant theories of pain. In turn, these theories lead us inevitably to the realm of contemporary biomedical pain theory; which is complex and introduces the new terms of *nocigenic pain*. The term, Nociception, means the response to noxious (noxa/damage) stimuli. As any anaesthetised patient demonstrates, this is not necessarily synonymous with feeling pain.

In our contemporary view, Sensory input comprises four modalities: (1) nociception, (2) mechano-reception, (3) thermal reception, and (4) proprioception. The perception of pain results from the stimulation of nociceptors. Nociceptors are located in skin, muscle, fascia, blood vessels, tendons, joint

capsules, ligaments, fat pads, periosteum, and in visceral tissue where they respond to stretch and distortion of visceral organs. In structure, they are free nerve endings. Stimulation of nociceptors results in afferent impulses conducted through myelinated A-gamma and un-myelinated C fibres passing through the dorsal root ganglion. Polymodal nociceptors respond to chemical heat and pressure (C-fibre afferent), or heat and mechanical stimuli (A-gamma-2 afferent). Modality-specific mechanoreceptors (A-gamma-1 afferent) are the slow adapting nociceptors, responding to strong pressure. A-gamma fibres produce well-localized first pain sensations associated with immediate injury. In contrast, C fibres carry diffuse burning second pain sensations that can be dull, poorly localized, and persistent. C fibres then, are significant in chronic pain.

Hyperalgesia or sensitisation occurs when intense and repeated stimuli from tissue damage or inflammation are present. This results in a lowered threshold for activation of primary afferent nociceptors (PANs), which leads to innocuous stimuli causing severe pain. For example, slapping someone who has sunburn on the back or swallowing when one has pharyngitis can be very painful.

### **2.1.3.b Neuropeptide and Neuroeffector Functions**

In addition to transmission of afferent signals, nociceptors also have what are termed neuroeffector functions; via various mechanisms they affect the message, which they conduct. When activated by a noxious stimulus, they release neuropeptide from their cell bodies in the dorsal horn (e.g. substance P, calcitonin gene related peptide [CGRP]) that act on peripheral cells. Most of these neuropeptides modulate the afferent response.

Noxious stimuli aside, PANs (or primary afferent nociceptors ) can also be activated either primarily or secondarily by inflammatory mediators, neuropeptides, or other pain-producing substances. Stimulators that have been implicated in this process are many and for the purposes of this paper only those that are more prominent will be mentioned.

Bradykinins, which are released following tissue damage, act directly on PANs to cause pain, as well as sensitising them. Protons, associated with the decrease in pH following hypoxia in tissue injury, excite and sensitise PANs. Serotonin, histamine, prostaglandins, cytokines such as interleukins and nerve growth factor, adenosine, substance P, nitric oxide and neutrophils amongst others directly or indirectly stimulate PANs to produce hyperalgesia, often through activation of different PAN receptors.

### 2.1.3.c Transmission of Signal

Two major pathways transmit the pain signal centrally: the spinothalamic tracts and the spinoreticular system. The spinothalamic tract, comprising ventral and lateral components, transmits aspects of acute pain (e.g. location, intensity, quality) and alerts the individual to biologically threatening events. The spinoreticular system, on the other hand, mediates autonomic and affective reactions to pain. These pathways are responsible for overall alertness, vigilance, and fear surrounding any noxious stimuli.

From cell bodies in the dorsal horn, the direct spinothalamic tract crosses to the anterolateral white matter of the spinal cord and ascends through the lateral edge of the medulla, lateral pons, and midbrain to the ventrobasal region of the thalamus. From here thalamic neurons project to the somatosensory cortex.

The ascending fibres of the spinoreticular system terminate in the brainstem reticular formation, pontine, medullary areas, and the medial thalamic nuclei. This tract contributes to affective processing of nociception by connecting ascending information from the brainstem to limbic structures, via the noradrenergic bundles. Nociceptive impulses ascend to the locus coeruleus (a pontine nucleus near the fourth ventricle) and then ascend via the dorsal adrenergic bundle to the cortex.

### 2.1.3.d Chronic Pain Theory

Individuals in varying circumstances perceive pain produced by similar noxious stimuli differently. There are, for example, many stories of soldiers who have endured extensive wounds with little experience of pain while in the field. Moreover there is the placebo phenomenon that is apparent in chronic pain. Implicit in these observations is the realisation that the central nervous system is able to modulate incoming nociceptive signals. Melzack and Wall were the first to postulate this phenomenon in their gate control theory discussed above.

Supraspinal descending signals modulate nociceptive input, but from where and how? Reynolds in 1969 demonstrated that stimulation of the periaqueductal grey (PAG) matter allowed painless surgery to be performed. Mayer and Price then in 1976 confirmed that higher centres clearly modulated nociceptive input from damaged tissue. It is now known that descending inhibitory messages can originate from several areas in the central nervous system, including (1) the corticodiencephalic and diencephalic system; (2) the mesencephalic, periaqueductal grey, and periventricular grey area; (3) the medullary centres, including the nucleus raphe magnus; (4) the spinal and medullary dorsal horns; and (5) the descending pathways from the locus coeruleus via the noradrenergic pathway.

The mechanism of activation of these various pathways has been a subject of great interest.

Endogenous morphine-like compounds have long been suspected and more recently endogenous opiopeptide anaesthetics have been described. Opioid receptors have in turn been found on neuronal cell membranes. Opioids and so presumably endogenous opiopeptides bind to this receptor that is found throughout the brain, at central sites, brain stem, and spinal cord, to alter pain perception.

Other factors such as emotional stress, arousal, and attention can alter the response by involving central mechanisms. A network linking the hypothalamus with the brainstem has been described, which is sensitive to opioids, influences dorsal horn neurons, and triggers their ascending nociceptive transmissions.

Chronic compression of dorsal roots or peripheral nerves (as seen in herniated intervertebral discs) causes pain by a marked increase in their mechanosensitivity. Findings from animal models led to the conclusion that chronic compression of nerve roots can increase repetitive firing of that root, which is caused by low threshold mechanical pressure.

Phantom limb pain, causalgia, and selected peripheral nerve injuries are thought to be caused by loss of inhibitory controls. The brainstem reticular formation is thought to exert tonic inhibitory influences on transmission at all synaptic levels of the somatosensory system. This tonic ability depends on normal sensory input. Loss of normal sensory input after amputation, peripheral nerve lesions, emotional stress, and use of certain drugs impairs the efficacy of this mechanism and leads to increased pain. Chronic stimulation by adding normal sensory input back to the injured area through electrical stimulation (i.e. TENS), acupuncture, or nerve blocks inhibits activity of self-sustaining interneuron pools and may reverse this phenomenon and decrease pain.

### **2.1.3.e Sympathetically Maintained Pain**

The involvement of the sympathetic nervous system in pain started with the syndrome called reflex sympathetic dystrophy (RSD) or causalgia. It was noted that some patients with peripheral nerve injuries (e.g. causalgia), fractures, soft-tissue trauma, myocardial infarction, or stroke developed severe burning pain in the region of the injury. Blocking the sympathetic nervous system often relieved the pain.

The exact mechanism by which the sympathetic and primary afferent nociceptors (PANs) interact is not fully understood, related findings can be summarised in the following manner. A noxious stimulus from visceral organs releases substance P and can stimulate afferent neurons and depolarise sympathetic ganglion cells. In somatic afferent fibres it has been demonstrated that after peripheral nerve damage or inflammation sympathetic nerves interact with PANs to cause transmission of pain.



During inflammation, sympathetic fibres are stimulated and release prostaglandins, which in turn stimulate the PANs causing pain.

PERIPHERAL NERVOUS SYSTEM	CENTRAL NERVOUS SYSTEM
<ul style="list-style-type: none"> <li>• Sensitisation of peripheral neurons.</li> <li>• Unmasking of silent nociceptors.</li> <li>• Collateral sprouting</li> <li>• Increased activity of damaged neurons and their sprouts.</li> <li>• Invasion of dorsal root ganglia by sympathetic postganglionic fibres.</li> </ul>	<ul style="list-style-type: none"> <li>• Hyperexcitability of central neurons (central sensitisation)</li> <li>• Reorganisation of synaptic connectivity in spinal cord and elsewhere within the CNS.</li> <li>• Disinhibition – removal of tonic descending inhibitory activity and other mechanisms.</li> </ul>

Table of possible mechanisms for chronic pain (after Asburn and Staats, 1999, 1866)

## 2.2 PSYCHOLOGICAL THEORY

### 2.2.1 AFFECT THEORY 1900

The development of sensory physiology and psychophysics during the twentieth century gave momentum to the concept of pain as a sensation and overshadowed the role of affective processes. The sensory approach to pain, although valuable, fails to provide a complete picture of pain processes.

Affect theory dates back to Aristotle who considered pain to be an emotion – the opposite of pleasure – rather than a mere sensation. At the turn of the nineteenth century, Marshall, a philosopher and psychologist, argued vehemently against both von Frey's specific pain receptors and Goldscheider's pattern theory. Instead, he postulated pain to be an emotional quality that coloured all sensory events. This type of thinking added a new dimension to the study of pain that psychological researchers have subsequently explored extensively.

### 2.2.2 PSYCHOANALYTIC THEORY 1940-1960's

According to psychoanalytic views, idiopathic intractable pain is a defence against unconscious conflict. Emotional pain is displaced onto the body where it may be more bearable. Szasz and Engel were the first to propose theories stressing the importance of psychological factors at a time when the biomedical model described the standard intervention for all pains. Szasz (1957) proposed that the ego perceives the body as an object, such that the individual reacts to the body as something outside of the self. Thus, feelings are projected onto the body as though onto another person, with pain experienced as a hostile attack inflicted on the suffering individual.

Engel (1959) offered a developmental theory to explain "psychogenic pain". From the time of birth an individual builds a "library" of pain experiences, originating from pain caused by peripheral stimulation. Thus, throughout development pain acquires meaning from the context in which it initially occurs. These meanings themselves may later become triggers for pain in the absence of peripheral stimulation.

Following on from these psychoanalytic theories extensive literature was forthcoming which aimed to show that emotional problems generate and perpetuate chronic pain.

### 2.2.3 BEHAVIOURAL AND COGNITIVE THEORIES 1970's

Although the philosophical roots of behaviour (peripheralist) and cognitive (centralist) theories may seem irreconcilable, they often complement each other in the study and treatment of pain.

Following the work of Skinner (1953), behaviourists tried to show that all behaviour could be shaped, altered, weakened or strengthened as a direct result of environmental manipulations. Fordyce et al



(1968) were the first to apply the behavioural model to pain. Behaviour theory defines pain by the presence of "pain behaviours", that is, observable actions. According to Fordyce (1978), acute pain, which he termed, "respondent", is a reflexive response to an antecedent stimulus (tissue damage). The respondent pain may eventually evolve into chronic or what he called operant pain if the environment offers pain dependant reinforcement. Behavioural explanations thus propose that chronic pain persists because of it elicits secondary gain, for example avoiding chores, aversive family interactions or permits control over family members. Pain behaviour may also be learned by observing "pain models". The high incidence of pain and illness in family members of pain patients is cited as evidence for this.

Cognitive approaches to the treatment were largely inspired by the gate-control theory of Melzack and Wall, which was discussed earlier in this review. Since the mid 1970's proponents of cognitive theory have studied the meaning of pain to patients, and examined the effects of coping styles on pain. Intervening variables such as expectations, beliefs, self-efficacy, personal control, attention, problem solving, coping, self-statements and imagery and how these thought processes impact on the experience of pain and related problems are examined in cognitive studies.

Behavioural and cognitive behavioural approaches have both been used extensively in pain programmes during the last 15 years with some successes reported. Purely behavioural interventions aim to change pain behaviour by manipulating environmental variables. The behaviourists view is that changes in behaviour may themselves eventually modify the experience of pain. However programmes with a predominantly operant focus are rarely purely behavioural in that they also teach cognitive skills (Sternbach, 1989). Cognitive strategies, in contrast to purely behavioural ones, attempt to change the way patients think about pain and to increase the patient's feeling of control over all aspects of the problem. Interventions which combine behavioural and cognitive approaches aim to help patients restructure the way they think about their pain as well as increase their day to day activity.

In 1994, Jensen (*et al*) published an article in the journal, *Pain*, on the relationship of pain specific behaviour to chronic pain adjustment. Based on research conducted on 241 patients, the results indicated that a number of pain related issues are showed associated positively with psychosocial dysfunction. These included that emotions affect pain and that others should be solicitous when pain is experienced. These results thus support the value of a cognitive-behavioural model of chronic pain adjustment.

#### 2.2.4 PSYCHOPHYSIOLOGICAL/ PSYCHOSOMATIC THEORIES 1980-1990'

Psychophysiological studies examine the effect of mental processes (thoughts, memories, emotions) on the actual physical changes that produce pain. The theory is complex but if we consider general arousal

models, they propose that the frequent or prolonged arousal of the autonomic nervous system, including prolonged muscular contractions, can generate and perpetuate pain.

Treatments such as EMG biofeedback and relaxation techniques are designed to decrease levels of muscle tension and autonomic arousal, and thus reduce pain. Such treatments have been found to be effective in reducing muscle contraction headaches, migraine, and back pain, although not more than psychological interventions

In a pilot study by Ventegodt *et al* (2003), 19 patients with chronic pain showed dramatic short-term results after a one-week course using teaching on life philosophy, psychotherapy, and body therapy. Body therapy is any bodywork bringing awareness to areas in the body. This is believed to have the effect of turning physical pain back into the original psychological pain, which can then be processed in psychotherapy. These patients suffered from conditions like fibromyalgia, chronic tiredness, whiplash, mild depression and osteoarthritis. The study showed an overall 11.2% improvement in quality of life. Symptoms like pain almost halved with several participants being free of pain for the first time in years.

### 2.2.5 PSYCHIATRIC ILLNESS AND CHRONIC PAIN

In a population-based study of nearly 2000 people Benjamin *et al*, (1999) determined that psychiatric diagnoses were present in 16.9% of patients with chronic widespread pain compared with 11.9% of the general population. Cause and effect were not demonstrated.

## 2.3 MARRYING SOMATOGENIC AND PSYCHOGENIC WITH INTEGRATED ASSESSMENT

Most physicians tend to see pain as caused either by organic pathology, or if this is not present, psychological factors must be causative. Turk and Okifuji (1999) suggest that physicians need to discard the conventional dualistic notions of chronic pain. They make the point that chronic recurrent pain, specifically, is modulated by the patient's way of coping with symptoms and current mood, as well as by the response of other people including the physician and family members. Understanding and appropriately treating a patient with chronic pain, therefore, requires an accurate assessment, not only of the tissue damage that may be the cause of the pain, but also specific psychosocial, behavioural, and psychological factors such as current mood, interpretation of symptoms, expectations about the meaning of symptoms and responses to the patient's symptoms by others. Each of these aspects contributes to the patient's subjective report. An individual's report of pain reflects multiple contributing factors, such as cultural conditioning, expectations, mood state, and perceptions of control.

### 2.3.1 LEARNING THEORY - WHO HAS THE ABILITY TO CHANGE?

Pill and Stott (1982) examined the issue of taking responsibility for one's own health, by, for example, accepting that one may be accountable for falling ill and for maintaining one's health accordingly. They found that willingness to accept responsibility can be seen as depending partly on the person's views about aetiology of illness and partly on their perceptions of factors constraining behaviour. It follows that if a person's concept is that illness is caused by an external phenomenon they are unlikely to view personal responsibility as important.

These authors proposed three possible hypotheses explaining why an important sector of society appears resistant to adopt feelings of responsibility for health.

1. That a sector of society is immutably resistant to change and so fixed in their ways that personal changes are unlikely to be achieved. This is an overtly fatalistic hypothesis and has little data to support it – though it is possible that a subgroup in each society is totally opposed to adaptation: imposed or chosen.
2. That more innovative health education and promotion can achieve better results with the "resistant" sector of society.
3. That a large sector of society is trapped in socio-economic circumstances that render lifestyle change either impractical or irrelevant, however much the individual may desire to change.

The desire to make changes as well as the opportunities to do so did seem to co-exist in the sample studied.

### 2.3.2 ACCUPUNCTURE

Acupuncture is thought to work by involving the spinal gating mechanism, resulting in segmental pain relief. The insertion of an acupuncture needle stimulates afferent nerves that cause interference (closing the dorsal horn gate) of the pain signal to central connections.

Another possible mechanism of action may be by interacting with endorphin levels. Clinical investigators have tested chronic pain patients and found that they often have lower than-normal levels of endorphins in their spinal fluid. Investigations of acupuncture include wiring the needles to stimulate nerve endings electrically (electro acupuncture), which some researchers believe activates endorphin systems. Further experiments with acupuncture have shown that there are higher levels of endorphins in cerebrospinal fluid following acupuncture<sup>1</sup>.

Acupuncture didn't make headlines in the United States until the mid-1990s when the Food and Drug Administration upgraded acupuncture needles from experimental status to full-fledged medical devices.

<sup>1</sup> See the NINDS Chronic Pain information page 07/2001

Then the National Institutes of Health found evidence of acupuncture as an effective treatment for nausea caused by anaesthesia and chemotherapy; as well as postoperative dental pain and a number of other pain related conditions; either alone or in combination with other therapies.

Testing the scientific validity of acupuncture using double blind trials poses difficulties. This however hasn't kept scientists from finding creative ways to test acupuncture's potency. For example, a German study, published last year in the *British Medical Journal* (2001), weighed acupuncture against massage in the treatment of chronic neck pain. Over three weeks, 177 volunteers received five 30-minute sessions of massage, needle acupuncture, or fake acupuncture (researchers used an inactivated laser acupuncture pen in lieu of needles). Afterward, 57 percent in the needle acupuncture group reported considerably less pain. In comparison, only 25 percent of those who received a mere massage saw an improvement. The authors concluded that acupuncture is "a safe form of treatment for people with chronic neck pain and offers clinical advantages over conventional massage."

In another clinically controlled study, Italian researchers enrolled 120 migraine sufferers to compare the benefits of acupuncture with those of drug therapy. Over the course of a year, volunteers were either given a maximum of three courses of 10 acupuncture treatments twice a week, with a one week break in between, or varying rounds of conventional drug therapy. The results, published in the *Journal of Traditional Chinese Medicine* (2000), showed that at six months the acupuncture group had an 80 percent drop in migraine symptoms, while their pill-taking counterparts reported a 46 percent dip. This said, perhaps the best news was that the acupuncture group reported no side effects, whereas more than 75 percent of those in drug therapy had troublesome reactions.

### 2.3.3 THE EVOLUTION OF MULTIDISCIPLINARY PAIN CLINICS

The awareness of a need for a multidisciplinary approach to chronic pain can be traced back to the Second World War, when doctors from various disciplines were drawn together to care for soldiers. Conditions such as painful phantom limb, and other post amputation pain syndromes, as well as causalgia and reflex sympathetic dystrophies and myofascial pain syndromes posed a great challenge to neurologists, surgeons, anaesthetists and other physicians involved. The writings of people like Leriche, Livingstone and Mandl (24) introduced the useful idea of blocking nerve pathways with local anaesthetic.

Shortly after the war pain clinics began to be established; the first documented taking root in the United States. Normatively, these clinics comprised an anaesthetist, neurosurgeon, orthopaedic surgeon, psychiatrist, physician and radiation therapist.



For the next two decades the idea of a multidisciplinary approach lay dormant. Two developments changed this: Melzack and Wall's *Gate Control* theory of pain (1965), and the *International Association for the Study of Pain* (IASP, 1974). In 1977 when the first directory of pain clinics was drawn up, 32<sup>7</sup> multidisciplinary pain clinics existed in the western world (60% in USA and 20% in Europe).

Working in the USA, Asburn and Staats (1999), published an article in the *Lancet* on the management of chronic pain. They see the multidisciplinary team as comprising a physician, psychologist, nurse, physio and occupational therapists, vocational counsellor and pharmacist.

### 2.3.4 THE EXPERIENCE OF PATIENTS WITH CHRONIC NON-MALIGNANT PAIN.

A single study was found that is similar to the research that follows. This was by Seers and Friedl (1996) who reported on patients' experiences of their chronic non-malignant pain. Seventy five people were investigated with the aim of evaluating the effect of relaxation training after training both immediately and long term. It was primarily a quantitative study but had a minor qualitative component in order to provide greater insight into what it meant to people to experience chronic pain. Qualitative data was gathered at the same time as quantitative at a baseline interview, at the end of teaching 1 and 4 months later. Field notes were taken during the semi-structured interviews and then extensively written up after the interview. These included comments made by the patient and the researcher's own impression of the interview.

In their findings they reported nine common themes related to chronic patients' pain experience.

1. experience of health care
  - believing the pain
  - treating chronic pain as if it were acute
  - desperation of the doctors
  - blame
2. psychological states
3. physical health states
4. relationship with family/friends
5. social activities
6. employment/finances
7. comments on relaxation and describing
8. comments on pain

## 9. lack of personal control

Seers and Friedl (1996) concluded that the qualitative data deepened their knowledge of the patients' experience. Moreover they found that pain adversely affected many dimensions of sufferers' lives, and the effects extended to family and friends. Having others believe the pain was crucial to many patients, they noted. Health care professionals need to talk to their patients about the meaning of their pain in order to help improve their quality of life.

## 2.4. SUMMARY OF LITERATURE REVIEW

This literature review investigated the major theories relating to the cause of pain.

Somatic theories in essence inform that one of our four sensory input receptors is to noxious stimuli. These receptors are called nociceptors, are located in many tissues, and in structure are free nerve endings. These nerve endings comprise differentiated fibres that each respond to different noxious stimuli. The intensity of the transmission signal is then modulated by many different factors. Repeated stimulation to these afferent neurones lowers threshold to pain. Neuropeptides secreted by the nervous system, inflammatory mediators from the blood and many other proteins secreted also modulate this afferent response. Supra spinal nerve signals via endogenous opioids from different parts of the brain as well as emotional states all influence perceived pain.

Psychological theory dealt with a behaviourist model, how environmental factors influence pain e.g. chronic pain remains because of secondary gain; and cognitive theory, how one thinks about pain e.g. increase feeling of control over all aspects of the individuals life limits pain felt.

Psychosomatic theory takes cognitive theory a step further by saying for example that repeated negative thoughts leads to stress which in turn cause repeated muscle contractions that perpetuate pain.

These theories lay the foundation for an aetiological chronic pain theory called an integrated assessment, combining the somatogenic and psychological approaches as well as looking at broader factors like cultural conditioning and meaning of the pain.

This multifaceted thinking led to the development of multidisciplinary pain clinics.

Another similar qualitative study by Seers and Friedl was then discussed. These findings indicated similar themes to the research here presented, as well as patient's need for other to believe their pain. This study was also found useful for the depth of insight gained into the patient's experience of pain.

The following chapter presents the methodological aspects of this study.

## Chapter 3: METHODOLOGY

This chapter discusses and motivates for methods used in this study. It starts by discussing the early changes that occurred in the course of this research, why a qualitative method was chosen and where the study was conducted. It then moves on to elaborate on sampling, study tools, data analysis and ethics.

### 3.1. EARLY STUDY DEVELOPMENT

The initial pilot study altered the early aims and objectives of this research. My first plan had been to use a semi-structured interview to examine paradigm shifts in chronic pain sufferers. However, as discussed fully in chapter 5, this narrow focus was found to be limiting, much like examining a detail up close before standing back and viewing the picture. For a subject as subjective and complex as understanding chronic pain a different research tool was then explored, a qualitative approach.

### 3.2. MOTIVATION FOR QUALITATIVE RESEARCH METHODOLOGY

The defining feature of qualitative research is that it seeks to describe and analyse people *from the perspective of those who are being studied*. This methodology is most appropriate for this intended study because

- It is exploratory research, (that is, relevant concepts are unknown.)
- It requires explanatory depth. The emphasis being on meaning and understanding the person and how they experience their pain. The study of humans is different from the study of nature because it involves subjective understanding.
- It requires a flexibility of approach so as to allow for the discovery of unexpectedly important topics. As was demonstrated following pilot interviews, questions posed and methods used needed to change as new information was collected. This is closely related to the overall approach of qualitative research which is to understand the perspective and world view of the informants.

With all this in mind then I acknowledged and set aside my beliefs regarding the importance of an internal locus of control and entered the research with openness to the stories of the patients.

### 3.3. STUDY LOCATION

Participants for this study were selected from patients attending Cape Town's Groote Schuur Hospital Pain Clinic. This clinic is a specialised referral centre for doctors in both the public and private sector providing assessment and recommendations for the management of patients suffering from chronic pain. Patients often attend the clinic once many other sources of care have been exhausted.

The clinic team comprises a psychiatrist, a psychiatric social worker, a nursing sister, two anaesthetists, and, more recently, a psychologist practicing cognitive-behavioural therapy. Because of budget cuts, the team lacks a physiotherapist and occupational therapist. The policy of the clinic is to act as an opinion resource for non-specialist caregivers, believing that their primary care doctor best manages chronic pain patients, however difficult this might be to effect. Probably because of feelings of inadequacy or lack of knowledge, referring doctors seem hesitant to manage their patients who have ongoing pain (discussion with Dr Baumann GSH pain clinic.)

### 3.4. SAMPLING

A pilot study consisting of 6 interviews with patients took place. These interviews were not included in the study. Five patients were selected for the study using purposive sampling. This form of sampling is usually used in order to include a enabled the identification of informants wide range of types of informants, as well as key informants with access to important sources of knowledge or experience. This small study size allowed for in depth exploration of themes that arose, which resulted in saturation of data.

The sister in charge of the clinic was asked to select informants based on the following selection criteria:

(1) The informants should be well known to the pain clinic and have an interesting story, as well as (2) they should be able to express themselves and their relationship to their pain in good English. And (3) they were required to have consulted previously with the clinic psychiatrist.

Some patients at the clinic are managed mainly by the anaesthetist with epidurals and nerve blocks. For others psychotherapeutic interventions and medication from the psychiatrist play a greater role. Most patients move with ease between these two approaches. The third selection criterion was used in an attempt to ensure that patients selected were exploring the psychological aspects of their pain.

In retrospect, comparing the sample with those of a similar study, the patients selected were particularly extreme examples of patients living with chronic pain. The nurse selected "good examples" of clinic patients – who ended up having extreme experiences of chronic pain. In addition it is possible that



prior consultation with a psychiatrist may well not have been synonymous with the patient exploring the psychological aspects of their pain, but rather the referring doctor's perception that a psychiatric disorder was present.

As researcher, I introduced myself as someone with a particular interest in chronic pain. This allowed me to be perceived as independent of the clinic and not necessarily implicated in any negative or positive feelings that might be felt towards medical personnel. In the pilot studies, I found this a particularly useful strategy as it freed me from being consulted and also allowed me to probe deeper into the patient's understanding of their problem without the assumption (from myself or them), that being a doctor, I should know the answers to their questions. If however a patient did ask my occupation, as one did, I acknowledge that I was a doctor. If the patient asked advice I explained that in this context my role was as a researcher and advised that they ask the clinic doctor about their problem. All this said, it is accepted in qualitative research that the researcher will always influence the data attained. The researcher then is expected to acknowledge the context of the interview by means of extensive field notes and actively taking biases into account. This process is known as reflexivity, (Mays & Pope, 1995.)

### 3.5. RESEARCH TOOL: INDEPTH INTERVIEWS

During the course of the pilot studies, the study tool was changed. The initial semi structured interview guide was found to have limitations, as discussed above. From there, the study used in-depth unstructured interviews with a single introductory question and then reflexive remarks and probing of patient's ideas and feelings.

According to Pope (1995), in-depth interviews are "face to face conversations with the purpose of exploring issues or topics in detail. Rather than using pre-set questions, objectives are shaped "by a defined set of topics or issues " (Pope, 1995, 43.)

The researcher conducted all interviews. The technique used is very similar to the patient centred model of consulting with which the researcher is very familiar. The introductory question was; "Tell me the story of your pain?"

Interviews were conducted in a consulting room along the corridor from the pain clinic section. These sessions were tape-recorded and later transcribed. Field notes contributed to the non-verbal and contextual aspects of the interview and setting. The interviewers own thoughts and feelings were included in field notes. The field notes were used later to back reference and to retest reliability.

### 3.6. DATA ANALYSIS

This proceeded in three stages: data reduction, data display and analysis.

The contents of the scripts were systematically coded and categorised for recurrent themes that arose, and then analysed by constant comparison. This is essentially an “iterative process of developing categories from the transcripts or field notes, testing them against hypotheses, and refining them.” (Mays & Pope, 1995, 184.) Evidence from the data was then used to support conclusions reached.

Analysis was by the qualitative method, *inductively*, that is deducing hypotheses from the data, using *grounded theory* (Straus & Corbin, 1990; Pope & Mays, 1995; Charmaz, 2000.) Inductive methodology places great emphasis on the credibility or truth of the *meaning* of the findings, this is called *internal validity*. For Pope and Mays (1995) this internal validity is considered more critical than either the finding’s conceptual certainty or its external validity.

“Under the strictures of grounded theory, the findings must be reached through a systematic account of the setting that would be recognisable to the people in the setting while at the same time being more structured and self-consciously explanatory than the participants themselves would produce,” writes Mays (1995,111).

In writing up this research report, a chapter was devoted to writing up the major themes. These themes were grouped into nine main subcategories. The data thus captured were the experiences and explanations of particular patients, in particular circumstances at a particular point in time, with a single interviewer.

#### 3.6.1. Reliability

The main way in which qualitative researchers ensure reliability of their analysis is in maintaining meticulous records of interviews and observations, and by documenting the process of analysis in detail. This method was pursued. Two different researchers agreed upon themes separately.

#### 3.6.2. Validity

Using a process known as triangulation, this researcher has attempted to validate inferences drawn by comparing one data source with another. Triangulation refers to an approach to data collection in which evidence is gathered deliberately from a wide range of different, independent sources and often by different means. Using in-depth interviews as the major source of information, I also referred to the clinic notes and attend the multidisciplinary meetings after the pain clinic in which the patients were

discussed by all the clinic staff. Pain authors as well as primary sources of information gleaned from my months of attachment to the pain clinic were other methods of triangulation employed.

### 3.7. ETHICS

Informed consent was obtained verbally, and in private, from the informants by myself.

Protection of anonymity was guaranteed. Taped information was coded with only the researcher, namely myself, having access to participant names.

The protocol was submitted and approved by The University of Cape Town Faculty of Medicine Research Ethics Committee.

Permission for access to the pain clinic was obtained from the person in charge. The Medical Superintendent was informed in writing of the research project.

With this methodology in mind we now move on to the following chapter that covers the findings of this research.

## Chapter 4: RESULTS

This chapter can be divided into the following broad themes: (1) the experience of pain, (2) the experience of treatment, (3) coping with pain, (4) perception of causation, (5) impact of pain on the family, (6) impact of pain on self, (7) feelings regarding the future, (8) doctor-patient relationship and (9) patients' expectations of doctors.

By way of introduction, a brief synopsis of each patient interviewed is first presented in tabular form below. This assists in providing a context for the findings that follow.

1. Mr M
<ul style="list-style-type: none"> <li>Mr M is a 40-year old married father of four, a religious Muslim man. He suffered neck pain of unknown cause for three years before he had his first operation, a spinal decompression, in private practice. He then developed a hydrocephalus and required a ventricular peritoneal shunt. His medical aid had by then run out and this was undertaken at Groote Schuur. After this surgery his pain became very much worse. He is now on morphine and waiting to see if the doctors can offer him some relief with an epidural block. He previously worked for an engineering firm but is now unemployed because of his constant pain. His main concern is being unable to provide financially for the education of his children.</li> </ul>
2. Ms. C (Pretender / Fighter)
<ul style="list-style-type: none"> <li>Ms. C is a 38-year-old married mother of two. She is unable to work because of her pain and is supported by her husband. She developed chronic pain following surgery for a slipped disc of her lumbar spine. Regular epidurals offer her some relief. She gave me good insights into her personal relationship of living with the pain. She was also quite controversial as she had strong feeling about distrust of doctors and claimed to know about a conspiracy amongst some of the clinic patients against the clinic. She seemed to enjoy the position of secretly mistrusting and blaming the doctors, with her band of fellow patients.</li> </ul>
3. Ms H (angry)
<ul style="list-style-type: none"> <li>Mrs H is a 55 year old Muslim divorcee. She lives with one of her 7 children and has a small business selling clothing as well as her disability pension. She is a tall attractive expressive person, who walks with a stick and commands her world with it. She has had two marriages and eleven pregnancies in all.</li> <li>Her story started in 1974 when she sustained a back injury after twisting her ankle, a minor injury. She had recurrent pain from then until her first surgery in 1983 a discectomy. She then returned to work and did well until 1989 her back deteriorated badly. The cause of the pain was unclear. She finally had surgery that was given a 50% chance of success; she understood it as a lumbar 4 and 5 disc removal. She did well after this and return to work. Then she developed a lump on her foot dorsum, a ganglion. She went in to have surgery on the foot but discovered that in theatre the surgeon who she had been handed over to by her professor was not around and instead she had an unknown surgeon. Mobilising from this surgery was extremely fraught and the pain set in. From that time on the pain escalated. Then the secrets emerged about what really happened in theatre that day. She learned that her spine had "collapsed" in theatre and that no one had told her. From then things deteriorated with multiple rejections and no hope prognoses from doctors who told her they "won't touch" her. She was sent to a psychologist who angered her and he confirmed for her suspicion; "Why did they lie to you?"</li> </ul>

4. Mr GF (clown)
<ul style="list-style-type: none"><li>Mr GF a married father who lives with his wife and children. Had coronary bypass surgery in 1989 with septicaemia cause by a blood transfusion administered against his will. He then developed non-union of his sternum and developed chronic pain, initially at this site, later lateral chest pain and back. Other past medical history is of diabetes, insulin dependant, hyperchlosterolaemia and previous non alcohol induced pancreatitis.</li><li>This was one of my early interviews and so was more structured than the others.</li><li>He is a jolly chap who likes to cheer up others in the pain clinic .I saw him as the clinic clown. His wife was passive and seemed submissive agreeing with him but never venturing her opinion. He, on the other hand, seemed convinced of his position and sure in his opinions, to the point of being overbearing</li></ul>
5. Ms. C (Pretender / Fighter)
<ul style="list-style-type: none"><li>Mrs. CD lives with her two daughters, is in the process of getting divorced from her estranged husband who has a younger woman, with whom he has a child. She sat knitting throughout the interview in a sweet, benign matriarchal sort of way. She sees herself as a victim and her diagnosis of pain in some way justifies her helplessness. She earns money from letting out property she owns.</li><li>Her pain came from a prolapsed disc, initially managed conservatively and later repaired surgically. Her pain never really settled from then and she had multiple nerve blocks, and epidurals offering no relief. Her husband had an affair at the same time as this was going on and complicated the resolution greatly.</li></ul>

Table 4.1 a synopsis of each patient interviewed

4.1. THE EXPERIENCE OF PAIN

The individuals’ experience of their pain was a central theme that was raised by every interviewee. This experience sat at the core of each person’s incapacity, and it is from this pivot that everything else related to the pain spiralled outwards. What follows is a description of various sub-themes that fall herein.

4.1.1. Sleepless nights

Every person interviewed mentioned that they had problems sleeping due to their pain. The desperation associated with insomnia is illustrated in the following quotes.

*“If I sleep for an hour at night or 1½ hours then that’s it. Most of the time I walk up and down, sit in the armchair, up, my head and my body. I can’t take it.”(M)*

*“Night and day having sleepless nights because of pain. Even taking sleeping tablets, I don’t sleep at all.” (exasperation was emphasised by her tone of voice)(CD)*

*“Don’t sleep at night, so I fight with myself to go and sleep and the longer I fight with myself to go and sleep, I cannot sleep. So, it’s an extension of time that I don’t sleep at all. I feel awful with myself. I feel cross at myself already cause I cannot sleep which is frustrating” (C)*



Each respondent had their own way of describing the intensity of the pain or their response to it.

#### 4.1.2. The Drama and Madness of the pain

Ms H experienced a sense of emergency and drama. She related chaos and confusion as she was “rushed” to her GP and then “rushed” to Groote Schuur. A picture emerged of someone crazed with unbearable pain

*“And when they touched me apparently I shouted so wildly .....r” ... “and pain, pain, pain” (H) (H)*

“Apparently” implies that she didn’t remember shouting,

Three times in her interview Ms H described a feeling of madness because of the intensity of her pain. She grimaced and groaned and repeated the words “in pain” eleven times during the interview. At one point she was crying because of the intensity of the pain experienced during the actual interview.

*“Sunday I went bonkers with pain. Bonkers with pain”*

*“Cause now the pain is beyond me.”*

*“then I shouted and shouted and pain and pain and pain and pain” (more and more emphasis)*

#### 4.1.3. Helpless with the pain

Ms H angrily described herself lying in hospital in pain. She was injected with morphine but had no relief. A picture emerges of a victim helplessly enduring this relentless pain. As no relief has been forthcoming resilience had worn thin and the pain worsened.

*“And he came, he gave me morphine and that was that. And there I lay. And then I lay. Morphine. Pain. (Said in an angry voice)*

*“And since 1994 I’ve never been pain free. It’s actually so worse now”. (H)*

M describes being overcome by worsening pain; he speaks of himself as becoming weaker as the pain grows stronger.

*You getting weaker and the pain getting more, the pain is getting to you, really, and I’m not that type of person who complains about the pain whatever. I just take what’s coming, but it’s just worse now honestly. It’s just worse, worse now (M)*

#### 4.1.4 Pain resulting in isolation and distancing of relationships

Pain was seen as an alienating experience. All respondents raised the issue of relationship difficulties because of the pain.

Ms C describes her experience of aloneness:

*"Your husband cannot help you, your children cannot help you, you just grow further from them. "But how it's not easy for people to say if they not in your position. They don't feel your pain, they don't go through your pain, it's a totally difficult" (C.)*  
*"I stay away from even my best of friends, I don't want to see them because I hurt so much." (GF)*

The husband of one respondent became unfaithful when she became ill.

*"Since my accident my husband had a affair with a girl twenty years his senior (sic), a girl old enough to be his daughter. Um. I had to deal with that as well" (CD)*

The family may learn to live with the person's alienating behaviour.

*"Now my wife and my children understand, so say if I get acid, they take it with a pinch of salt" (GF)*

#### 4.1.5. Metaphors used to describe the pain and pain experience.

The pain is seen as something external that intrudes:

*"the pain is getting to you" (H)*

Sometimes the pain forces action:

*"I mean who wants to come to hospital at that time of the morning, the pain is driving (me) there and I've got to get someone to bring me" (M)).*

Mr M sees the body as a vessel that can only hold a certain amount of pain.

*"The way I see it is your body can only take a certain amount, so much of pain. And after that when it cannot, it cannot take that pain any more – something might just happen. It just might. (He later spoke about his fear of being paralysed if the pain became too severe for his body to handle)*

Pain is seen as an invisible enemy against whom one fights:

*"It's like fighting something that you can't physically see, It's fighting. It's a constant fight with yourself all the time" (C.)*

#### 4.1.6 Patients' Hopes about Pain

It was the endless intensity of chronic pain that people found so debilitating. Each respondent wished for an end to be in sight.

Mr M mentions hope seven times during his interview. His hope is always that the medical profession will bring him relief.

*"Honestly, I'm just hoping that they can do something, that they can do something for me. Now I'm only hoping that they can do something now really" (Silence) (M)*

A repeated wish was to just be able to live a normal life. To do the ordinary daily tasks that they used to be able to perform.

*"I'll be very glad. If I could just do the things I'm used to doing." (M)*

*"I wanna walk, because this is my life" (H)*

#### 4.1.7 Despair

The other side of hope is the despair mentioned in some guise by all the respondents.

*"(Desperate whisper). And I went home after about three weeks, 4 weeks, maybe longer. I can cry. I can really cry. They took away everything. Damn you. Now I've got pain 24 hours around the clock." (H))*

*"But I've still had the pain constantly every day" (M)*

For Mr F the desperation and agitation is so severe that he becomes aggressive and even has aggressive thoughts towards himself.

*"I can get to stage of agitation when I will start hitting out". (GF)*

*"There are that I want to take my gun and put it to my head and blow my head off" (GF) (mention again in "the future".*



#### 4.1.8. Need for the pain to be witnessed / acknowledged

Patients expressed great distress when the other, particularly a caregiver, did not perceive their pain as real.

When Ms C. refused an injection she perceived that her health carers response was disbelief of her pain. She thus elects at times not have a consultation but to just collect her medication.

*"I told him " Dr but I do, I have pain." But I refuse the injections. "I said " but I don't want them because they made me worse." That's why when I don't see Prof, I'll just ask them for medication." (C)*

Ms H perceives referral to a psychologist as undermining the authenticity of her pain.

*"I don't act. I don't need the psychologist because they gave me an appointment with the psychologist again and I didn't go. Because I know exactly what I'm talking about. I'm a mature grown-up woman. I know I had 3 double spine operations," (H)*

*"My husband wouldn't make the tea because he just wouldn't accept the level of pain that I was in". "He denies it completely" (CD)*

*"My own parents don't accept it. And I'm ignoring them"(CD)*

Ms C. manages this lack of validation by using self- assertive techniques learned at a pain management workshop.

*"And to think, to realize that you have the pain and whether people tell you, you have pain or not, you've got to tell them but I do have pain. You've got to be, oh how could I put it now? You've got to be honest with yourself and deal with it, that you do, and when people become rude to you, you should stand up for yourself and not back out. (Silence) And I never ever knew" (C)*

Mr GF experienced a lot of validation of his pain from his wife. She sat next to him during the interview, saying nothing, nodding supportively at what he had to say.

He sees himself as the soldier who bears his pain silently. However he still communicated a need to compete with a fellow patient over the severity of their pains.

*"I said to the one lady waiting here this afternoon I says" what's wrong with you". She says "I've got pain here in my hip (whispers) it's my nerve." I say "and it's dragging your lip right down to the ground". . I says, I'll tell you what's wrong with me and then you tell me if you've got more pain than me". "She says "and what's the matter with you?" I says "I've got a sternum that's not joined; and do you know what a broken leg is like?" She says, "Yes, I've have one". "Well I've got a broken chest bone" I says "and they can't fix it"*

He seemed to need to be validated as the “silent sufferer”; He wants to have the severity of his pain acknowledged, but also to be seen as brave soldier who suffers in silence. He continued his report of his conversation with a fellow patient;

*“So she looks at me, she says, “You must have a lot of pain” I says, “Yes I do but I’m not showing it to you.” I says “the minute I show it to you I’m looking for sympathy and I don’t want your sympathy.”*

#### 4.1.9 Fears and Fantasies

Mr M feared that the intensity of the pain might lead to paralysis.

*“You know what happens, the pain gets so worse I’m just afraid that something might happen that I might not be able to have the use of my arms again or whatever, that’s how worse the pain gets”... It just might, like getting lame, you know, not being able to use the leg and arm, or whatever or being paralysed afterwards.” (softly)(M)*

#### 4.1.10 Cursed

Ms H expressed a belief that she was cursed with this pain and as such untouchable.

Speaking in a whisper, she related what her doctor told her:

*“But your spine is damaged Mrs H. This pain will never ever leave you now.”*

*“He said to me ‘sit down’. I sat down. He sat there and he said ‘listen to me, I won’t touch you” (whispers) And I look at him I said to him, ‘Come again?’ he said to me ‘I’m not touching you. I don’t know why they sent you to me but I’m not touching you’. “*

## 4.2. EXPERIENCE OF TREATMENT

### 4.2.1 Failure of Surgery

All five respondents underwent surgery with the aim of treating their initial pain. However the surgery did not relieve their pain.

*“But in any case I had this first op ‘83, they removed some disc, whatever and I went home. But it was never, you know, always pain. (H)*

Three out of the five respondents experienced the surgery as making the pain worse.

*"After two, not small operations, it was big operations of the upper spine. And after two operations I'm worse off than before."*

M related his response to the doctor explaining possible outcomes of surgery:

*"I can live that, if that's all, you promise me that's all. I can live with that. But, now that never materialized, I'm more sore than before. It makes me feel angry. It makes me really angry" (M)*

*Initially when I had my first operation it affected my right leg. And it has affected both my legs now that I even; I feel I am limping because my left leg is shorter than my right now. (C.)*

*"Eventually the disc broke into pieces and they had to operate cause it fell onto nerves, so they had to operate. And then a few weeks after the op I had, um, I had pain coming on again,"(CD)*

#### 4.2.2. Ambivalence about the surgical intervention.

*"And I discovered afterwards from a house doctor that the operation they did wasn't necessary". (GF)*

*"And at the time my father didn't want me to have the operation" (H)*

#### 4.2.3 Treatment as exhausting and resulting in despair

Four out of the five respondents expressed that their treatment seemed endless and exhausted them, and had then left them with a sense of despair. They had had it all and nothing worked.

*"Um I had all the test, you name it, and um epidurals and whatever and I laid there. ... Now they're been giving me epidural, epidural, epidural, you name it I get epidural." (H)*

*"But the pain is there, the headaches are there, and I don't know from here what they intend doing or going from one doctor, like I told this other doctor, that I've seen earlier on, I get sent from a Prof to a neurologist, from the neurologist to see another doctor" (C.)*

*"But you still have the pain there although you do, you take medication upon medication, its like why do you still take the medication cause the pain is forever there. Pain. So why must I still, it's like exerting myself more."(C)*

*I had about, one two.... three epidurals, being injected, steroid injected into my spine to alleviate the pain, which it didn't, the pain came back. And um then when I came here Professor did another procedure. That also didn't help, and a funny part of whole thing is every time when the pain comes back, it's ten times worse." (Pause) (CD)*

#### 4.2.4 Treatment as persecutory

A patient described her position on the operating table as *"and I was like crucified"* (H), a metaphor of torture. Respondents expressed a sense of being acted upon – rather than being active participants in the decisions

*"Now they're been giving me epidural, epidural, epidural, you name it I get epidural."* (H)

*"I get sent from a Prof to a neurologist"* (C)

#### 4.2.5 Experience of Morphine

Patients experienced morphine as only minimally effective or ineffective, and the cause of a number of side effects, (not all of which relate to side effects known to be caused by morphine)

*"When I take the morphine it first takes that sharpness away of the pain, but it consistently there, and my hand starts swelling along with the pain, then I can't use my hands at all."* (M)

*"You know taking the morphine it makes me drowsy, and when something makes you drowsy you either got to sit down or you got to sleep, but because of the morphine that take that sharpness away of the pain, but the pain is still there. But taking the morphine it doesn't work for me. That's all, it doesn't work. Because you not taking the morphine for your health whatever. But you've still got the response"* (M)

*"Cause the morphine that avoids you of doing what you need to do."* (M)

#### 4.2.6 Treatment perceived to be effective

Ms C was the only respondent who mentioned that a change in her own psychological approach to her pain resulted in more effective pain control.

*"Last year in July, I attended a pain management clinic, which is an excellent clinic. It helped me tremendously to cope with my pain. It taught us how to, relaxation programme, how to deal with certain stress, and if Groote Schuur could offer those to more pain patients, chronic patients, it will be a very good idea. By giving you today just how to think positively about yourself. If ...um and not to become a pain yourself to other people".* (C)

Mr GF found the attitude of his caregivers gave him relief. He differentiates pain in his mind from the pain in his body.

*"Between L and Dr. they control my pain. I feel when I come to them I still have the same pain when I leave but it subsides in my mind because they're always positive at what they are trying to do for me"* (GF)

Local nerve blocks were found to be partially effective, as were the oral analgesics

*When Dr gave me the injection there was relief, not completely but there was relief. No I don't know how strong the injection was whatever, that he gave me. I don't know the strength of the injection but there was relief. (M)*

#### 4.2.7 Perception of being used as 'Guinea Pigs'

Three of the respondents raised examples of incidents that had left them with a sense of being experimented on by their doctors. These experiences undermined trust between the doctor and patient and left the patient feeling a victim of the medical profession whose main aim was their own agenda, not the patients well being.

Mr M had a concern that his neurosurgeon had performed his procedure for the first time.

*"If this going to be his first operation? ...And that was my concern. That was always my concern and I never said it to him, I never said it to him at all, because if he had any other operations similar to this before, if he had done, then I don't believe, honestly I don't believe that I would be suffering like this". (M)*

Ms H speaks of a new imaging technique to which she was exposed and then an experimental operation, done as a teaching exercise for junior surgeons. The significance of this for her was that it made her feel special to her professor. Later in the course of her illness this same "experimenting" might have heightened her anxiety of what could have gone wrong.

*"The machine was coming from England and he said you've got to sign. It's almost like a guinea pig thing"*

And then about her surgery:

*"It's very delicate its very like usually they say 50 to 50"(H)*

When the doctors were talking about her they referred to her as;

*"The one with the very dangerous op" and "Prof used to phone me to come in for his students". (H)*

Mr GF felt that the physiotherapists who wanted him to do some exercises were experimenting him on,

*"Leave me alone and stop using me as a bloody guinea pig." (GF).*

### 4.3 COPING WITH PAIN

#### 4.3.1 Psychological attitude to pain

##### 4.3.1.a Control

Ms C mentioned the issue of taking control over the things she can control.

*"I know I'm still in full control of my life, although I have pain. I am in control of my life. And like I told the other doctor, I have lived to deal with my pain. (C)*

##### 4.3.1.b Being positive or assertive.

Ms C also spoke of effective ways to relate to herself and her pain. She found that validating the pain for herself and not being undermined by the attitudes of other people was useful. She also found that is helped to have a positive attitude.

*"By giving you today just how to think positively about yourself. If um, and not to become a pain yourself to other people" (C)*

*"And to think, to realize that you have the pain and whether people tell you, you have pain or not, you've got to tell them but I do have pain. You've got to be, oh how could I put it now? You've got to be honest with yourself and deal with it, that you do, and when people become rude to you, you should stand up for yourself and not back out. (Silence.)(C)*

Mr GF also mentioned that his thoughts played a role in controlling the pain.

*But then when the thought goes away again there it is, you know it's your mind that really controls your body. I'm so convinced about it it's not funny. (GF).*

##### 4.3.1.c Minimizing the symptoms

Another coping strategy employed was to underplay the symptoms of pain in order to cope.

*I don't... if they would ask me 'Mommy why are you limping?' and I'll say, 'It's just a small nerve pinching.' Although I know I cannot even step on my one foot. (C)*

Ms C chose to hold her suffering to herself.

*"I keep it inside of me Although I don't show people I have pain, my face doesn't say I have pain, I keep it inside of me."(C)*  
*And I have dealt with that, that although I have pain I would pretend, that you know, the pain is there but I can live with it, you know it can become very stressful (C)*

#### **4.3.1.d Using Humour and Fortitude to manage pain**

Mr GF had a different coping mechanism to the other respondents. He played the role of the clinic clown and then tried to show others how he was coping by bearing his pain.

*"I'm totally bugged up (laughs). ...I've always had this spirit in me. Since I was a little boy I teased..."*  
*I say 'the minute I show it to you I'm looking for sympathy and I don't want your sympathy'." (GF)*

#### **4.3.2 Love relationships ease pain**

Mr GF found the love he received from his wife helped him to cope with his pain.

*"So the most dedicated medicine for a person with pain is somebody to love them. Somebody to be there for them when they're in need. It's a little thing but it breaks down the constant hurt. He talks to me then my mind goes away from the pain,"*

#### **4.3.3. Behaviour that may help the pain**

##### **4.3.3.a Exercise**

Two respondents mentioned the role of exercise and though they had been taught that it would be useful in pain relief it was found to have a limited benefit.

*"And I never ever knew walking helps for the pain and that's since then I tried to walk as often as I possibly can, and exercising, because for me doing exercising while I had pain, I wouldn't do it. And that's what they taught me. It helps for the pain"(C)*

*"I walk quite often. And I haven't been exercising because ... I've become despondent to be honest; you know whether I do the exercises or not I still have the pain. I won't say it doesn't really work. It helps, I'll say 5% it helps,"(C)*

##### **4.3.3.b Reading**

Three of the respondents mentioned reading as helpful

*"And when I have lots of pain I read."(C)*



#### 4.4 PERCEPTION OF CAUSATION

Each person spontaneously explained the way they understood the cause of their pain. All 5 respondents attributed their current pain to surgery, and each had their own vivid image of what was happening in their bodies to maintain the pain. Mr GF gives a mechanical view of what is causing the pain.

*"1989 I had the heart operation. You see what happened I had a bypass, triple bypass, and my wound went septic, so they had to chip the bone away on both sides and its never joined, but they touch one another and say I bend over fast with my arm to try and do something, then the bones rub up against one another"(GF)*

The other four respondents all had back problems as the initial cause of their pain.

*"I had a laminectomy done through Dr X, a private doctor at Groote Schuur Hospital. About 10 days after that he told me I developed an inflammation infection there where the wound was, where he operated on. And ever since then I've been attending hospital, since that time till now, with having constant pain" (CD)*

*They told me my disc slipped and it went on to my right nerve, which he made me understand that a discectomy is something when you put a surgical thing in. I don't know how ... that is and then when I had the second operation" (CD)*

Two of the respondents also mentioned not knowing what had caused the first pain and that the doctors had also been uncertain as to the nature.

*"And I twisted my ankle. I can't really explain how it happened but when, um, I came back up stairs and when I went to the wardrobe to open the wardrobe I couldn't move. They could find out what was wrong with the right side, but they couldn't find out what was wrong with the other side." (FI)*

*"Before the operations I don't know what. I might have hurt myself, I really don't know"(CD)*

Ms FI had a dramatic understanding of the cause of her ongoing pain. She mentioned a number of factors that were related to causation. She relates that she was told:

*"Well you know what's wrong with you? Your spine collapsed in theatre."(FI)*

She pointed out areas on her ankle and scalp and, with a sense of mystery and horror, told me that they were the bundles of nerves that caused the pain.

*"What is this? What's wrong with this? (Pointing to a lump on her scalp)." So he said to me "I'm going to tell you something. That's a bundle of nerves"".*

Mrs H also attributes her pain to being operated on by someone other than her usual trusted doctor. There's a sense that she sees this being-let-down as the cause of the ongoing pain rather than the competence of the surgeon who did the operation.

*"She could have phone me and said, 'Mrs H, listen we cancelled the op'. And she gave my op to another doctor and then afterwards the pain, I was so in severe pain."*

On a number of occasions it became very likely that details of events or explanations had become distorted or that misconceptions had occurred:

*"And then I laid here, then in 3 something, about 6 months with traction on my legs (H).*

*"I was told that's also a bundle of nerves (pointing at her foot) and this is also a bundle of nerves (pointing to her head, sounding fearful). Where does it come from sweetheart? (In a frightened voice) (H)*

*"... Understand that a discectomy is something when you put a surgical thing in. I don't know how" (CD)*

#### 4.5 IMPACT OF PAIN ON FAMILY

All five respondents mentioned the negative impact the pain had on their family.

Ms H mentions the fear of her children and grandchildren when she is in pain.

*"I started to get delirious and they don't know what's going on around me, the children started to panic and they phoned for the ambulance" (H)*

*"I got dizzy and my granddaughter of 6, 7 was in the room and as I came in she asked me "Mama, what's wrong?" (H)*

Mr M expressed his distress about not being able to work and so provide for his family.

*"It's so frustrating for me not to do what to do. And I mean I've got responsibilities as well, I've got a family, I've got 4 children and it gets to me at this stage (M)*

CD minimised her pain, presumably in order to prevent her family's concern.

*"If they would ask me 'Mommy why are you limping?' and I'll say, 'It's just a small nerve pinching.' Although I know I cannot even step on my one foot." (CD)*

All the respondents mentioned the day to day practical help that they receive from their families.

*"That girl inside – that's my cousin, she comes through from Bridgetown almost every day and if this pain is down the leg she's got to bath me, she's got to shave me" (H)*

*"Dress myself, my children must help me dress, or she's (her cousin) got to help me put on my panty" (C).*

## 4.6 IMPACT OF PAIN ON SELF

### 4.6.1 Multiple losses

Respondents experienced a multitude of losses due to the pain. This included loss of sexual intimacy, enjoyment of life, independence and self-image. In addition there was financial loss and loss of abilities such as memory.

#### 4.6.1.a Loss of intimacy and enjoyment of life

*"13 or 14 years I've never had sex, nothing" (H)*

*I'm only be 38 and it's frustrating for a woman. I mean I still want to enjoy life to its fullest but I cannot do so because of the pain " (C)*

#### 4.6.1.b Loss of independence also resulted in loss of privacy:

*"She's got to bath me, she's got to shave me, I'm Muslim I've got to be clean." (H)*

*"There are times I am really down in bed with my back when I cannot even get up to do something for myself. Dress myself, my children must help..." (C)*

#### 4.6.1.c Loss of previously held self-concept

This was expressed as follows:

*"Really, and I'm not that type of person who complains about the pain whatever. I just take what's coming, but it's just worse." (M)*

*I'm very strong, I'm a very strong person, but for this 9 years now, I've got weaker. (Silence) It's terrible man. Honestly, I don't want a person to have a worry or to cause or whatever, then it would be fine for a person like that. But I'm not that type of person. I'm not that type of person at all, that why it worries me so much."* (M)

#### **4.6.1.d Loss of function**

Ms H in particular complained about loss of memory.

*That's why I can't, I can't remember, can't remember a lot, and then I can't even remember everything."* (H)

Other losses mentioned related to practical things like driving, work, walking, and difficulty with parental responsibility.

*"You know I've been driving my own car and whatever and since 1995 I have problems driving in my own car. I can't sit too long, I can't drive too long or and in 1994 I had to give up my work cause I couldn't take it anymore, I couldn't take it anymore (M) and I'm not able to do a lot for me"* (I)

*"But you've still got the responsibilities at home, that's what I'm saying. I'm a father I've still got those responsibilities."* (M)

#### **4.6.1.e. Financial losses**

Four of the six respondents mentioned the financial strain associated with their illness.

*"But you've still got the responsibilities at home, that's what I'm saying, and it's very frustrating for one, especially I have 2 children which are very young still, I married, I'm not working, and I've always worked before, and I don't. There are times I feel useless because I cannot contribute towards my family". Silence. "Financially?" "Yes". (CD)*

*I've left my job whatever. It's only money going out - there's no money coming in, because of my health. I'm trying to get the things but it just doesn't work for one because of my health, and aah, I don't know. I'm only hoping...* (M)

*"And it has affected both my legs now that I even, I feel I am limping because my left leg is shorter than my right now". (C)*

## 4.6.2 Gains

### 4.6.2.a. Maturity – survived triple back op

Ms H saw herself as a survivor. She related being referred to as *“The one with the very dangerous op”*

She is able to affirm herself in terms of her ability to withstand surgery.

*“For a woman that had such a, 3 double spine operations, you’ve got willpower. You’re one helluva fantastic woman. You’ve got willpower.”*

*“This is my life and I’m not going to give it up for anybody” (H)*

## 4.7. THE FUTURE

Living with the fact that the pain was incurable was a burden and talk of the future was met with pessimism in all the respondents.

*“I know I will have pain like people have been telling me, physiotherapists, professors, doctors, whoever, that I will have pain for the rest of my life. I will have the pain for the next, next 20 years, next 30 years - I don’t know, which is a very, very sad thing to think of” (C)*

*“... Makes the future look very bleak for you, very dim, there’s nothing for you, but ah that’s why I don’t let my mind wonder about it anymore” (CD).*

*“Because I, actually I’m only 40 years old. I’ve still got my whole life in front of me, whatever. And I cannot, it’s so frustrating for me not to do what to do. And I mean I’ve got responsibilities.” (M)*

*“There are that I want to take my gun and put it to my head and blow my head off” (GF) (mention again in “the future”.*

## 4.8. THE DOCTOR-PATIENT RELATIONSHIP

Given that these interviews were conducted in the building of Groote Schuur Hospital just outside the pain clinic, it might have been difficult for patients to speak frankly about their negative feelings towards the medical profession. Despite this, negative experiences were commonly expressed, and ranged from what seemed to be simple misunderstanding, to perceived maliciousness on the part of the doctor.

This research is about the experience of pain and its management exclusively from the patients' perspective. It does not attempt/claim to give an objective account of the interaction between doctors and patients at the clinic. The interviewer did not specifically ask about dissatisfaction with caregivers, or about relationships with caregivers. The following responses were volunteered when inquiry was made into the patients' experiences of pain.

#### 4.8.1 Specific relationship difficulties.

Some patients had quite specific ways of relating.

Ms H related to doctors as either good or bad. The professor was her good experience of a doctor/parent and most of the other doctors were experienced as bad. Prof looked after her but all the others betrayed and misled her.

*"Just do the op, Prof, man. So he said 'you really got faith in me', so I said 'I do. I've got faith in you. And you did the first op and it was fine. (H)*

Ms C experienced a power struggle with her doctor. The doctor responded to her refusal of a regional block by refusing to believe the validity of her pain. She saw the doctor-patient relationship as adversarial. She even refused to see any counsellors for fear of being construed by the doctors as mad.

*"That's why I only want to see Prof. I only want to see Prof to do a epidural on me. And even like this doctor, he told me one day I do not need any medication. I told him "'Dr, but I do, I have pain. But I refuse the injections'. I said 'but I don't want them because they made me worse'. That's why when I don't see Prof, I'll just ask them for medication." (C)*

#### 4.8.2 Negative Experiences of Health Care Professionals

##### 4.8.2.a Perceived Betrayal by Carers

Four of the five patients expressed a sense of having been betrayed or misled by the staff. One patient felt that the surgeon had misinformed him about the risk-benefits of surgery.

*"And you know, what was said never materialized by the doctor, what I was told. He said the only problem you will have 10% different feeling in the right hand. I said, I can live with that, if that's all, you promise me that's all. I can live with that. But, now that never materialized, I'm more sore than before." (M)*

Mrs C perceived antagonism between the patients and staff at the clinic. She felt that the carers in the clinic “discussed the patients behind their backs” and that the nurses prejudice the doctors against the patients that they see as having a bad attitude. It is uncertain whether she was referring to the multidisciplinary team discussions that take place at the end of each clinic.

*“In the pain clinic here, Um one patient get discussed with another doctor and I don't think it's something good, especially like today I've seen it, which is not good, which is not good. Because one person will, before I go and see this doctor they will warn this doctor already about my attitude, although I don't have an attitude problem.”* (C) She believes that this has broken the trust between patient and doctor.

#### **4.8.2.b Lack of trust in the doctor**

Mrs C spoke about the difficulty of being a patient with expectations of one's doctor to help in one vulnerability and yet not to be able to trust that the doctor has the patients' well being as the highest priority.

*“You can build a gap between you and the doctor and not be honest about it. Even like this one patient here, she doesn't co-operate with people. Because you do not have that doctor-patient trust any longer. ... then you've still got to deal with your pain. Then you've got to depend on [them].”* (C)

She said that she purposely holds things back in her interaction with her doctor because she might say something that is later used against her.

*“Even like with this doctor I pretended, I pretended a lot. I don't speak openly because I might just tell him something”.* (C)

#### **4.8.2.c Doctors perceived as dishonest / malicious / devious**

Mr M believed that his doctor lied to him. He proposed two possible scenarios. Either he was not warned of the risks involved in his surgery or when things went wrong on the operating table he was not informed. He feels that honesty would have been far easier to handle than these lies. He says that he could understand if the doctor made a mistake and would forgive him. It is the perceived dishonesty that he is unable to resolve. He wishes that he had the courage to go and meet with his surgeon and tell him this, but years have past and he never has.

*“Why can't these people be, you know, be honest. If you are honest and something happens to me afterwards I will leave it at that. But be honest! Be really honest. And I believed in what he said because he is the doctor. He is the neurosurgeon. . And if*



*he did something wrong, if he, if he, if he can be open with me... I've done something wrong. I lied I did something wrong. I mean that's not the end of the world."* (M)

Ms H also believes that her doctors have lied to her. She reportedly had her suspicions confirmed when a psychologist working in the pain clinic asked her why the doctors had not told her the truth. When she tried to mention this to the doctors they did not want to talk about it. She reports her conversation with the psychologist as follows:

*"Why did they lie to you?" And I looked at him and I said to him "What do you mean?" And he said to me "Why did they lie to you?"* (H)

Mr GF believes that the surgeon purposefully called him in for surgery while his house doctor was on leave, because he knew that his GP disagreed about the necessity of the procedure. Because he signed consent before the surgery he believes he has no case against the surgeon.

*"Because the physician that was treating me Dr. S, he wrote Dr. L a letter. I've got a copy of the letter at home. It says please don't do the operation I first want to treat Mr. F, to see if we can't alleviate the problem. And Dr. S went on leave and Dr L phoned me, he says "look you'd better come in now. He did my operation. So me and the medical profession most times aren't very good friends'."* (GF)

Ms H believes her pain was caused by something that went wrong in theatre that the doctors are not telling her. She believes that they are hiding evidence from her and has attempted litigation.

*"Now please why don't they tell me that something is wrong ....the doctors are hiding something? My folder got lost in Grootte Schuur. (Sarcastic tone). You want to know more? My folder got lost. I'm living on a folder now that's only in from 1994, I went to a lawyer, I wanted to make a case and I dropped it. It's not worth it man. Cause whats whats whats."* (H)

Mrs C suspected that after the doctors have sent her from one specialist to another, and none have been able to help her, they would then dismiss her as crazy

*"I get sent from a Prof to a neurologist, from the neurologist to see another doctor, and then to a psychiatrist and then to a psychologist, and at the end of the day they're going to tell me, you're nutty or you're looney, because it has affected my mind."* (C)

Ms I recalled an incident after her final operation when her doctor refused to believe that she had pain. He ignored her when she was trying to explain herself and discharged her. She went home and her pain became excruciating.

*"I said to him, 'doctor my left side is paining.' He said to me (she relates this in an aggressive abrupt loud voice) "It's your foot that pain. You're imagining your spine is paining". So I said to him "No, I know when I've got spine pain. This is my spine that's paining. "He said to me "It's your foot, but she's discharged." They sent me home, that's the Friday. And I went home and I was paining and paining." (H)*

Ms H describes her position on the theatre table as being "crucified". Her choice of words seems descriptive of how she felt. She made two further poignant comments about her treatment and the resultant pain.

They speak for themselves;

*"They took away everything."*

*"Damn you. I feel robbed." (H)*

Mr GF believed that a blood transfusion given against his will caused his septicaemia and subsequent mal-union that is the cause of his chronic pain.

*"Dr K came in and he says, "Oh, by the way I've got a pint of blood that you've got to take." I says, "Dr. I don't want blood" So he says to the nurse, the sister, he says, "give it to him anyway" so she went to put a drip into my veins".*

The health care professionals here were perceived as blatantly violating patient autonomy.

Mr GF described the physiotherapists, who were trying to get him to exercise, as sadistic. He was in severe pain and felt that they continued to push him further. He believed that they actually caused severe damage to his sternum by continuing work on him.

*"I am doing this and the tears are running down my face. And they're saying "Once more Mr. F, Once more Mr. F." It is a sickening thought, I thought that they were bloody sadists making me do that." (GF)*

#### **4.8.2.d Health Care Givers perceived as Abandoning**

Mr M who has experienced his surgery as a failure is now convinced that his surgeon is trying to avoid him. He has seen his doctor walking away from him down the corridors of the hospital and is sure that this is

purposeful avoidance. He feels angry, rejected and abandoned. He believes that if only he could meet up with his doctors and talked with honesty about what happened at the surgery, they would understand each other again, trust would be restored and it would feel okay.

*"And what hurt me more than ever, is that after the operation he's trying to avoid me at all cost. He's been sending me all over the show trying to avoid me. He sent me to the pain clinic,"* Later he says: *"he turns the other way, which makes me feel bad,"* and *"I'm sitting with the problem and he is avoiding it"*. (M)

Ms H expected the professor whom she knew, and who had operated on her previously, to do the operation. Instead another surgeon performed her surgery. In theatre when she asked where her doctor was her question was ignored.

*"Nobody answered me and then um, the op was done."*

It is worth noting that it is after this minor surgery for a foot ganglion that her original back problem suddenly deteriorates and her chronic pain starts.

*"Now why didn't she phone me and cancel the op? You get my point. She could have phoned me and said, "Mrs H, listen we cancelled the op." And she gave my op to another doctor and then afterwards the pain, I was so in severe pain."* (H)

#### **4.8.2.e. Health carers perceived as conspiring together against patients**

Mrs H later reported two separate experiences, one with a physiotherapist and then later with a psychologist, of being informed in a conspiratorial manner of the true cause of her pain. To make matters worse both these carers were about to leave public service work. This enforces her idea that now that they are leaving (her), they can risk speaking the truth. This truth is that the doctors have caused the problem and they are not telling her what happened.

*"So he said to me "I'm leaving here I'm going on my own private practice." Now why do they do that to me? This physio did that to me, and now the psychologist is also doing that."*

*'So he said, " Do you not know what you've got? Do you know what is wrong with you?" (Incredulous voice) So I said, "well they said to me unstable lower back, or whatever". So he said to me " Your spine, your lower back is broken. You've got a broken lower back." (Each word emphasized). Because you see Mrs H, whatever happened in the theatre, I don't know" (H).*

#### 4.8.2.f *Doctors perceived as rude*

Mrs C called the doctors rude. When she did not want to have further treatment that the doctors were offering, the doctor felt upset and treated her in a way she perceived as rude.

*"He was very rude to me one day, he was very upset with me because I told him I refuse to have" [the injections]. and "That doctors are very rude. One person even wrote a letter to the minister of Health". (C)*

#### 4.8.2.g. *Caregivers perceived as Rejecting*

Ms H mentioned at least six times in her interview different incidents when her health carers had told her that they did not want to touch her. She experienced these words as rejecting of her. Here the use of the words "this patient" distance and objectify her. She describes her Doctor saying:

*"We don't want this patient here, sorry" (emphasized & emphatic). "Send her back to ward where she came from". (H)*

And then years later when she goes to see her trusted professor, after the failed surgery by another doctor and this is how she remembers the conversation.

*"Listen to me, "I won't touch you" (whispers) And I look at him I said to him, 'Come again?' He said to me 'I'm not touching you. I don't know why they sent you to me but I'm not touching you. I'm sending you BACK (emphasized) to the pain clinic. Because there's nothing that can be done for you". (In a vindictive whisper). "Beautiful he". (H)*

The intonations and emphasis with which she said this make it apparent that this was an emotionally charged issue and touched a very deep rejected place within her.

#### 4.8.2.h. *A doctor always knows what's right*

Ms H initially believed her doctor to be infallible. She discounted her own symptoms because she understood her doctor to be denying them. She developed her own silent understanding of the cause of her pain and her symptoms deteriorated.

*"Listen to your doctor, because a doctor always know what's right." (Assertively)(H).*

### 4.8.3. Positive Experiences of Health Carers

Mrs C mentioned a doctor whom she experienced as empathic. Unfortunately this doctor had left. She expressed appreciation for the experience:

*"Because she is a person with compassion. She feels the pain you feel because she is a migraine sufferer. She know what it is to have a little bit of pain and I think its because she's a woman too. She handles the patient better. Unfortunately that's my point of view"(C).*

Ms H spoke of her relationship with her professor as one that meant a lot to her. She trusted him to do what she perceived as major experimental spinal surgery. All went well but then he handed her over to another doctor. She spoke with warmth about him as *"my prof"*, and described how he touched her as he said goodbye.

*"He said "you really got faith in me", so I said "I do. I've got faith in you".*

*"Prof, my prof is still standing there, Prof touch me, He said, "Mrs H, I put you in good hands. Dr M is going to do the op for you." So I said, "well thank you Prof."(H)*

Ms H became the professors' special patient and she recalled his praise of her:

*"You're one belluva fantastic woman. You've got willpower."*

Mr GF loves his two health carers at the pain clinic. They have rescued him from other practitioners who would have done him harm in his opinion and he is very grateful.

*"I've got two heroes in my life Dr. B and L. I love those two to death"*

He passionately told of how merely experiencing their care relieved his psychic pain, even if the physical pain remained unchanged.

*"I feel when I come to them I still have the same pain when I leave but it subsides in my mind because they're always positive at what they are trying to do for me". (GF)*

## 4.9. PATIENTS' EXPECTATIONS OF DOCTORS

This category is probably the crux of the issue when examining the intricate issue of the doctor/patient relationship. The respondents had all experienced a change in their expectations of their doctors during the course of their illnesses.

Some patients had ideas of how they could address grievances.

### 4.9.1 To Talk it out Honestly

Mr M had a wish to finally meet up with his surgeon and speak his truth. He had modest expectations of doctors now in relation to helping his pain.

*"What I really want to do is really to, to, to make an appointment to see him and have a chat. This is what I want to do. This is really what I wanted. And get out, that out of my system which I've been having all the time "* (M).

*"I've got some hope now when this doctor spoke to me, saying that he'd try to get the pain out of my body."*(M)

### 4.9.2. Doctors as Helpless

Ms CD has not been mentioned in this chapter yet because she did not bring up issues related to the doctor/patient relationship. She did however believe that, at times, doctors had nothing further to add to relieve her pain. Both from her regular clinic doctors and from the emergency unit doctors there are times when she realised that they cannot help her.

*"What is the use of going to hospital if they are going to give me exactly the same thing?"*

*"And I just thought, now, what's the use of going back now and telling the doctor. The pain is back."*(CD)

### 4.9.3. Doctors as fallible – but honestly so

Mr GF was very appreciative that his doctor would admit when he did not know what to offer next. He did not expect that his doctor would know all the answers.

*" Look, I'm going to do a little bit of research and I'll get back to you."*(GF)

Mr GF also had the view that doctors are not omnipotent and he has accepted that they are not able to offer him a cure for his pain. He quoted his doctor as saying:

*"Look, there's nothing, they can do for you'. So now I've accepted the fact "* (GF).



#### 4.9.4. Doctors should be honest, humble, and realistic

Mr M felt strongly that doctors should be honest and only what they were competent to do. Doctors should be brave enough to admit their failures to their patients. Doctors are human and so do make mistakes too. They should not avoid patients whom they have not managed to cure.

*"I don't know... he's got to be honest with me as well".*

Mr M mentioned seven times how he hoped that the doctors at the pain clinic would be able to offer him some relief. He did however expect his doctors to be realistic about what they had to offer him, even if it was modest.

*"... Hope that Dr MB and the other doctors can do something. I don't expect to be 100% well. But at least just get some of this pain away. That's all I need. The other pain I can live with." (M)*

*"You know I can't guarantee you nothing at all. I can't perhaps guarantee you a little hint of relief of pain" or whatever. But be honest! Be really honest." (M)*

This concludes this research's presentation of results. Conclusions are drawn in the next and final chapter.



## Chapter 5: DISCUSSION AND CONCLUSIONS

This chapter discusses the broad range of findings detailed in the previous chapter. After touching on my personal experience of conducting this research limitations of this study are discussed. This chapter then moves on to elaborate upon the four major themes that emerged from the grouped findings. These themes are ;(1) the experience of being in chronic pain, (2) and of treatment, (3) the doctor-patient relationship and (4) patients' expectations of doctors. When dealing with these important themes, I attempt to draw conclusions and then recommend interventions. Some discussion then follows, tying the themes together into what is termed here, "the shadow of modern medicine". Recommendations for future research are then ventured. The chapter is concluded with a tentative schema representing the cycle of chronic pain.

### 5.1. MY EXPERIENCE OF THE RESEARCH

This research was difficult as I was faced with stories of intense suffering – not only of the physical pain, but the emotions elicited by the pain. I heard stories that sounded incomprehensible, portraying my chosen profession in ways ranging from ineffective to cruel and malicious. I struggled between feeling sensitivity to my respondents, to protective towards my colleagues and cynical about the truth of what I was hearing. I had to remind myself that I was there to explore the subjective reality of the patients in order to have a better understanding of their experiences, and not to record objective data.

This black hole of intense negative emotion made this research aversive and draining for me as researcher. At times I was left wondering how to make sense of this, how I could respond in any way creatively, or helpfully to this barrage. I wondered if this was how so many caregivers before me had felt – and how this might have affected their doctor-patient relationship. It might be easier to just switch off, to avoid sitting with the human suffering expressed by patients who experienced chronic pain. In some way interacting with the patients and then rereading the scripts multiple times, reliving that experience, has felt as though it has changed me, leaving a sense of horror at the level of suffering experienced.

### 5.2. LIMITATIONS OF THE STUDY

#### 5.2.1. Limitations of Methodology

The initial pilot study altered the early aims and objectives of this research. The initial plan had been to use a semi-structured interview to examine paradigm shifts in chronic pain sufferers. The question I had wanted to ask was whether the ability to make a paradigm shift from perceiving the pain as having an outer locus of control to perceiving an inner locus of control is related to symptom control. Despite the months I had spent observing consultations in the pain clinic prior to conducting interviews, nothing proved more informative thus far than getting started.

For some patients the locus of control issue seemed relevant but not in the rational, logical fashion I had expected. One patient's perceived near death experience, which from a biomedical point of view was not in fact, near death, did result in a paradigm shift for him. He said, "suddenly things were more acceptable for me" and he went on to say he was saved by "trying to take control of the little bit of control that you still have" (HB). (This patient was interviewed in the pilot study and not included in the study sample), This said, for most patients, the locus of control seemed an irrelevant issue. For example; those with a better-defined biological reason for their pain, like chronic pancreatitis, who are managed fairly successfully with coeliac plexus nerve blocks or epidural analgesia - feelings of despair and depression were often expressed. For other patients' issues of betrayal and mistrust of doctors, feelings of anger, *inter-alia*, seemed far more accessible than issues of locus of control. I realised then that I had to broaden my approach in order to better understand the experience of chronic pain.

As discussed in the previous chapter, those questions arising from MJ's story, were found to be limiting when applied at a more general level to chronic pain patients. In the initial pilot questionnaire, it felt more as if I were examining some finer detail before the entire picture had been viewed. On reflection perhaps it might be true that those patients who had taken on a more internal locus of control would not be attending the pain clinic).

At a general level then, it seemed more reasonable to enquire whether people experiencing chronic pain represent our failures as modern medicine? If as *a priori* assumption we accepted that this is largely the case; that medical practitioners are failing to deal with an experience that is immeasurable in quantitative terms (because of its inherent subjectivity and complexity) the broader task at hand was one that sought to understand the suffering of those in chronic pain – rather than trying to answer questions at a finer level of detail. Instead I needed to first understand the stories of people living with chronic pain.

This alternative view corroborates with Morris (1991) who invites researchers to dialogue with patients about the meaning of their pain in general, rather than posing questions to patients based on a predefined script of questions focussed on a narrow set of research objectives.

Returning to the literature on qualitative research, it was apparent that this reworking of the research question often forms part and parcel of this type of research. The need to go backwards and forwards between the raw data and the process of conceptualisation is part of the research process - thus making sense of the data throughout the period of data collection.

### 5.2.2. The Sample

In retrospect, both the research site and the inclusion criteria resulted in a very specific and unique group of patients selected for interviews. The criterion of patients “well-known” to the clinic meant that they were patients who had either attended for a longer time or were “well-known” because of their personalities. The criterion that the patient should have an interesting story further characterises the group.

Another inclusion criterion, that the respondents had previously been seen by the clinic psychiatrist, rather than implying that they were in the process of exploring the psychological aspects of their pain, may well have reflected rather that someone felt that they suffered from a co-morbid psychiatric problem.

In addition, rather than selecting a broad range of patients, all informants suffered from pain that had not been relieved or had been worsened by surgery. To this extent four of the five respondents had undergone back surgery.

The sample therefore was a group of patients, well-known to a pain clinic, who had had unsuccessful surgery and who had attended a psychiatrist. This should be taken into account when looking at the findings.

### 5.2.3. Interview location

Interviews were conducted at the pain clinic. This, together with the fact that the interviewer was a doctor, may have inhibited patients from giving negative comments about their care. Although results seem to show that patients were not inhibited in this way, perhaps even stronger views might have been expressed elsewhere.

### 5.2.4. Validity

Analysed data from individual respondents was not taken back to them for verification. The reason for this was the considerable logistical difficulties involved.

## 5.3. THE PAIN EXPERIENCE

The descriptors used by patients for their experience were prolific and were expressed with marked emotional intensity - in words, tone and body language. Stories were emotionally charged and often extremely dramatic - such as descriptions of pain driving the person to insanity and for one, even the thought of violent suicide. All the respondents left me with an impression of pain being pervasive in their lives. Not a single aspect of their lives had been untouched and the pain was relentless. Not even sleep provided relief, and all found the pain experience alienating.

### 5.3.1. Insomnia.

All respondents mentioned the suffering and frustration caused by inability to sleep at night. Poor sleep has been proved to be a cause of pain (fibromyalgia) and a good night's sleep improves one's ability to cope with pain. Management of insomnia by both medical and non-medical means needs to be addressed in the management of chronic pain.

### 5.3.2. Helplessness.

In this sample, patients saw pain as an external force against which they felt helpless. Images of pain were of mechanical problems in the body, often in the context of relationships with health professionals having gone soured. Respondents saw health professionals as people who acted "on" rather than "with" them. Patients often saw themselves as both victims of the pain and the health professionals. In one situation, the doctor reacted with some hostility when a patient refused the regional block that he offered. The challenge is for joint decision-making in which the patient is an active member of the pain-management team. This may be more difficult with certain personality types, including those with high levels of emotional dependency.

I am also left wondering how the locus of control relates to chronic pain sufferers. In the instance whereby people who perceive that they are controlled by an external locus because they have not participated in their health decisions - could the bad experiences suffered have reinforced the victim mind-set?

The converse too seems to have a ring of truth. The two patients who functioned best interpersonally mentioned that their own control played a part in managing their pain. One mentioned how she was still in control of her life, despite the pain. She also mentioned that she had choices as to how to respond to her life, and choosing a positive response helped her pain. Possibly it was these individuals' responses that have facilitated rewarding interpersonal relating, or perhaps those with sustaining relationship do better in managing their pain. Regardless, emotional isolation and chronic pain do appear to feed off one another.

### 5.3.3. Isolation and alienation from family and friends

Pain is a lonely experience. "*They don't feel your pain, they don't go through your pain*". Trying to protect one's family by hiding the extent of one's pain can enhance the loneliness. Similarly the patient's irritability, which may be their response to pain and loss of sleep, can alienate the family. Family members are required to take on the personal care of the patient as well as their tasks. Some refuse, such as the husband who ignored his wife's pain and refused to take on even making a cup of tea.

Family-oriented management could address this isolation. The patient can be helped to communicate their experience of pain with their family in a clear way that releases the family from the burden of



responsibility for the pain or its relief (i.e. it does not sound like “complaining”.) In view of the burdens already placed on the family members by the need to help the patient with basic tasks and the taking on of new roles, family-oriented care could also help to distribute the load appropriately and prevent the development of overburdening individuals and family dysfunction. The balance between helping and inappropriately encouraging the sick role needs to be weighed up.

#### 5.3.4. Metaphors and images

Pain was seen as something acting on one – an enemy- that can overcome one if one does not ward it off. Expressive therapies could be used to enhance this view as being external and also allow the person to give it a name and shape in order to control it and reinforce it as something acting on one rather than defining whom one is. Some respondents referred to themselves as “*the one with the very dangerous op*” or “*I’m a mature, grown woman, I’ve had three double spine operations*”.

Mechanical descriptions such as “*eventually the disc broke into pieces*”, “*my spine collapsed in theatre*”, [that lump is] “*a bundle of nerves*”, indicate a simplistic view of how the body functions

#### 5.3.5. Despair with the pain, with the management

A major learning from this research is the depth of the despair expressed. The despair was with the pain and with the interventions (such as epidurals), which have not helped. Referral from doctor to doctor with no relief forthcoming was also a cause of despair. Visions of the future were bleak. “*I will have the pain for the rest of my life, I will have the pain for the next 20 years, next 30 years – I don’t know which is very, very sad thing to think of*” C.

Although respondents mentioned many emotions, the most difficult and potentially dangerous one was the despair: dangerous because ideas such as suicide were mentioned and difficult because despair can be easily transmitted between patient and doctor. The doctor’s ability to deal with the patient’s sense of despair requires a conscious self-awareness of his or her feelings. This is vital in order to avoid power struggles with patients, and eventual burnout. It requires us to maintain empathic understanding of the despair the patient is feeling, while avoiding over-identification. The doctor also needs to cope with his or her own sense of despair. This is not easy when the patient’s pain persists despite the use of all known techniques. Perhaps doctors need to accept that there are patients for whom very little can be done, but to be a witness to their pain. This said, to acknowledge that “doing nothing”, is doing something, in meeting the patients intense need for pain acknowledgment.

### 5.3.6. The Need for Acknowledgement

A theme that came up in some guise in every interview was the need for the pain experience to be acknowledged and / or witnessed. This finding is consistent with other research (Seers & Friedl, 1996). When we feel unheard, we tend to talk more loudly or we stop talking altogether. So for patients with chronic pain, perhaps their pain behaviour is a way of “talking louder” and the despair and depression set in when they choose to “stop talking”. Patients with chronic feel unseen and unheard. *“Your husband cannot help you, your children cannot help you, you just grow further from them. But how it's not easy for people to say if they are not in your position. They don't feel your pain, they don't go through your pain, it's a totally difficult.”* Acknowledging the pain relieves the loneliness of suffering. The person's pain becomes “seen”.

Being acknowledged allows containment. Much like the experience of a child who requires validation of its feeling reality from the mother in order to make sense of it, the chronic pain-sufferer longs for validation of their particular experience. The health carer and the immediate family play a pivotal role in bearing witness to the suffering and / or acknowledging it. Failure to do so can serve ultimately to undermine this relationship.

The acknowledgment that GF received from his wife helped him to make sense of his suffering and even find meaning in being the clinic clown, humouring the other patients. In contrast, H and CD, who had not experienced validation of their pain, were left floundering in anger and hurt. C had reached a further stage in the processing of the experience where she could hold and validate her own experience of the pain. She mentioned that regardless of others' response to her pain she knew that her pain was real and she would defend herself against it if required. This style of response would align with that of an emotionally healthy adult. This research thus suggests that health carers could help their patients by validating their experience of the pain as real. Possibly with enough mirroring of this over time, much like a child with enough emotional mirroring moves from dependence to independence, carers can facilitate such a move in their patients.

This idea derives from the psychoanalytic work of Wilfred Bion (1962) on “container-contained” relations. In this model the mother's mind acts as a container for her infant's projective identifications and in so doing, she is receiving her infant's unbearable and distressing emotions. In so doing she enables her infant to successfully deal with difficult feelings, providing her infant with the foundation to develop a capacity to think; in other words to deal with psychic reality.

## 5.4. THE EXPERIENCE OF TREATMENT

### 5.4.1. Surgical Intervention

Ambivalence around surgery was evident. One person had a father who opposed surgery and another's GP seemed to be against it. One person described the surgery with a sense of flippancy saying, "*They removed some disc, whatever and I went home*".

Another perception around surgery, which also undermined trust, or was perhaps an expression of mistrust, involved patients feeling "experimented upon".

All of the respondents underwent surgery with the expectation that it would help their pain. For each, this proved not be the outcome. One respondent believed that unnecessary surgery had caused his pain, and another three believed that surgery had made their pain even worse. It is well documented that scar tissue post back-surgery can cause chronic pain. As Dr Talbot says from her personal experience;

"Only after many consultations and investigations did I pick up a book and read about *Postdiskotomie-Syndrom*. I then began to understand that, although the nerve roots were not damaged directly by the surgery, they were now encased in a web of scar tissue causing pain and spasm every time this was tweaked enough by movements of the spine and legs. (2002, 985)"

It is impossible, and probably irrelevant to determine whether physical damage or psychosomatic causes, or both, were responsible for the chronic pain of these respondents. What does emerge quite clearly however is that surgical intervention failed to relieve the pain of all patients interviewed and that doctors and patients need to develop mechanisms to deal with this.

Two of the respondents mentioned that the initial cause of their pain was not known. This was either then, when the doctors were uncertain of the cause, or, because the patients had not understood the cause. As in the case of research by Seer's & Friedl (1996) and Siegal (1990), this work highlights the importance of the patient being psychologically ready for surgical intervention. Either surgical training needs to incorporate this aspect of assessing patient readiness, or patients that are suspected as being ambivalent need specific specialized assessment and counselling prior to surgery.

Four out the five respondents expressed their treatment as "*endless*", "*exhausting*" or leaving them with "*a sense of despair*". Many expressed powerful feelings of actually being harmed.



### 5.4.2. Morphine

In this group of patients, morphine was found to be ineffective against the severity of the pain and have unacceptable side effects – mainly drowsiness, which further limited the patients' abilities to function.

### 5.4.3. Pain Management Courses

One intervention that was striking in its perceived effectiveness was a pain management course that one respondent attended at the pain clinic. She recommended it highly for more patients. It was not clear whether the other respondents had attended but had not benefited, or never attended this course. The literature confirms that similar courses have been assessed and found to be highly effective.

Intensive "quality of life" sessions using a psychosomatic model have been found to be effective in reducing pain (Ventegodt *et al.*, 2003.)

A ten-week stress reduction and relaxation programme using mindfulness-based meditation for 90 patients with chronic pain showed statistically significant reductions in pain (Kabat-Zinn *et al.*, 1985). In addition the patients showed statistically significant reductions in negative body image, inhibition of activity by pain, symptoms, mood disturbance and psychological symptoms including anxiety and depression. Patients were able to reduce their pain-related medications, increased their levels of activity and experienced improved self-esteem. A control group of patients with chronic pain, who each received traditional pain management, did not show these changes. At fifteen months the group were shown to have maintained their improvements in all, but the present-moment experience of pain.

This feedback from the respondent in the study and the above evidence form a strong recommendation which needs to be taken up. This will require staff to be trained in running such groups.

### 5.4.4. Coping with Pain

Besides one respondent mentioned above who attended a pain management course, and some people trying a bit of exercise, or reading, there were few self-coping strategies mentioned. This was true even for Mr GF, despite his firm belief that the mind controls the body.

This leads one to believe that self-coping techniques do not arise very spontaneously for this sample of patients. Perhaps learned helplessness has been used as a coping mechanism, given the political situation in the past. It supports the idea that self-coping skills need to be taught and encouraged. This relates back to Pill and Stott's work on learning, which states that if a person's concept is that illness is caused by an external phenomenon; they are unlikely to view personal responsibility as important.

#### 5.4.5. Impact on self – Losses

Given the number of losses experienced by patients with chronic pain, one can accept that much grieving is happening. Depression is therefore likely. Grieving in itself needs to be acknowledged and supported as with any illness associated with loss (e.g. amputation). Perhaps this is a crucial aspect of pain management. The greatest loss is that of pain-free living, of going about our daily tasks in relative comfort. Like bereavement this may require spiritual guidance. Few patients mentioned spiritual aspects. Why me? What is the meaning of this pain?, Where is God?

As these are universal questions, it is perhaps surprising that they weren't mentioned.

Is there a need for spiritual counsellor at a pain clinic for pain that is not related to a terminal illness?

#### 5.4.6. Financial losses

Financial losses further impact on self-esteem, quality of life and stress. These were mentioned by every respondent. *"There are times I feel useless because I cannot contribute towards my family"* CD. Even if the person gets a disability grant, R740 per month is insufficient.

### 5.5. THE DOCTOR/PATIENT RELATIONSHIP

Given the circumstances in which these patients found themselves, (i.e. the quality of their lives significantly compromised by the intervention of doctors), it is not surprising that their relationships with doctors were characterised by loss of trust, feelings of betrayal and anger. However there seems to be more than simply that. Ms H's story certainly had some bizarre elements to it, and I quote from field notes. *"I was afraid and overwhelmed, intimidated by her and dread going back to her interview. In fact sitting with her for this period was agony as well as frightening because of her verbal and physical aggression. She did turn on me at times..."*

By comparison to the patients in the literature, the patients in this study seem particularly extreme examples of those with chronic pain. More than this, their homogeneity is compounded in that they have all had surgery, and this surgery has proven pivotal in exacerbating their symptoms. This is probably a result of the selection process in which the clinic sister chose the candidates. In addition they were long-term patients of the clinic and had consulted with the psychiatrist. From a certain viewpoint, this level of candidate uniformity could possibly be considered a weakness in this study. Conversely however, this "sweet spot" of similar patients suffering the same form of ailment allows for a deeper analysis of a problem that in many respects might have eluded this researcher had this not been the case.

All five respondents reported the experience of the doctor-patient relationship as an overwhelmingly negative experience with high levels of suspicion and mistrust. This is possibly the most significant

finding of this research. It requires further discussion in this paper and is also recommended for further research. In the previous chapter, the theme of negative experiences of carers comprised eight pages. This compared with the one page of positive experiences. Feelings of betrayal were mentioned by 4 out of the 5 of respondents; abandonment by some; and experiences of dishonesty from doctors by almost all. On six occasions, H mentioned that she felt rejected by doctors who “*did not want to touch her*”. Most respondents felt that their doctors had used them as if in some form of experiment.

On the one hand, we may say that patients who suffer chronic pain, may be predisposed to it by virtue of pre-existing personalities, and further research is needed in order to predict which patients will respond poorly to surgery and how best to prepare patients for surgery to have realistic ideas of the risk-benefits of surgery, and cope with possible failure of surgery to relieve their pain.

We also need to acknowledge the heightened sensitivity of these patients, given their pain, and perhaps personalities, and adapt our language and behaviour to avoid them experiencing the very alienating feelings that they experience. For example, it is known “*medispeak*” for a surgeon to express his or her ideas of surgery being contra-indicated by saying “*I wouldn't touch them*”. However, a vulnerable patient hearing this may perceive it as rejecting of themselves as a person.

Time under anaesthesia seems an especially vulnerable time for patients and it is possible that patients fantasize about what might have taken place. The presence of a known GP or nurse could help the patient, and doctor.

Keeping in mind the difficulty that such patients have in trusting their doctors, we need to be meticulously open and honest and especially careful about explaining everything we do. Joint decision-making should also avoid mistrust.

Although some information seems to tell us more about the working of the minds of the respondent (it seems unlikely that Ms H's back was broken in theatre during the removal of a ganglion from her foot), this research has identified possible unethical practices. Did, for example, a doctor really order blood to be given to a patient against the patient's expressed wishes?

In summary then, the primary tenet of trust between doctor and patient was not intact for each respondent. In the area of the doctor patient relationship, themes arose highlighting that patient expectations resulting from surgical interventions were a particularly fraught area. Expectations of significant reduction in pain level that were then unrealised post-operatively, created a negative spiral of pain out of which all respondents had been unable to break. This resultant suffering led to blame being

attributed to the doctor. None of the patients had experienced containment of their negative feelings: for example by being able to express them to the surgeon. Mr M mentioned more than three times that he wishes to talk to his surgeon about the surgery but has never been given the opportunity to do so. Over time, with ongoing physical pain and an unresolved emotional torment, most of the chronic pain sufferers seemed to spiral into an abyss of extreme physical and emotional and even spiritual pain.

One patient, H, told of how, after a relatively minor foot ganglion surgery for which her surgeon unknowingly appointed another surgeon to operate, her previous back problem suddenly deteriorated. It was at that point that her chronic pain started. There is a sense here of the patient feeling depersonalised by the health care profession, and that this impacted on the outcome of the surgery. Is her pain then an expression of unheard anger towards the health care profession? The idea arises as chronic pain being a "punishment for doctors". It can certainly feel like that! Reframed, letting the suffering spill over onto the doctor, is perhaps the only, and possibly most appropriate, place for it to go.

As Seers (1996, 1165) puts it, "since the situation is often complex the mismatch of expectations and perspectives between health care professionals and the patient, between what each wants and what is realistic, can lead to communication difficulties that serve to increase mutual frustration and alienation".

In many respects, these patients stand as representations of our failures as medical practitioners to meet our patients' needs. While this is not to say that suffering is not a part of the life experience, this research demonstrates that chronic pain sufferers believe they are worse off for our interventions. Their experience flies in the face of the most basic of our principle to first do no harm. As such, the sufferers' experience warrants further in-depth research as to when and how the course of "treatment" takes a turn for the worse. Morris (1991, 2) puts it poetically, suggesting that "medical voices need to enter into conversation with the more neglected community of voices speaking (with less authority but no less insight) about pain."

The patients experienced their doctors positively when they showed compassion and were positive. Praise from a doctor meant a lot to one patient. It makes sense that acknowledging a person's strengths will encourage those strengths and the patient's ability to cope.



## 5.6 PATIENTS' EXPECTATIONS OF DOCTORS

Within the doctor-patient relationship, an additional aspect is worth noting: the patients' expectations of doctors post intervention. Prior to any intervention, doctors generally carry superhuman projections around their abilities to heal. Post intervention, patients changed these expectations. M was interesting, in that he now moved between two positions: (1) that of accepting that his doctors cannot take away his pain, as he has presumably been told at the pain clinic, to (2) a quite desperate wish that they might at least be able to do something by way of pain relief. Again the issue of locus of control is raised. The doctors obviously offer something in the form of relief but the patient has control over the choices as to their attitude toward the pain. Here the idea espoused by Victor Frankel is important: that the last freedom we have is how we choose to respond. Other than this, patients' expectations of doctors were now modest, seeking only for honesty, and for doctors to know and acknowledge their limits. It is worthy noting that these are patients' expectations at this advanced stage of their illnesses, knowing what has gone before.

## 5.7. THE SHADOW OF MODERN MEDICINE: -WHEN TREATMENT AND DOCTOR-PATIENT RELATIONS GO WRONG

In the Jungian sense, chronic pain can be seen as the shadow of modern medicine; the darker inversion to all our technological advancements. In this sense, the term "shadow" implies a lack of consciousness about this side of our medical practice and ourselves. In doctors not acknowledging this shadow aspect of our practice, the patients default into carrying the emotional load. It has even been suggested that chronic pain is iatrogenic in nature (lecture given by UCT-based Dr Bowmann, 1997). This said, do we then actually cause chronic pain? I would argue that for some patients this is indeed the case: that, inadvertently or otherwise, as caregivers, our interventions have indeed caused the pain. Employing more integrated mind/body/spirit approaches, the caregivers might well have changed the outcome. This is a topic that requires more attention from us as doctors, both in the form of research and in the training of new doctors. With respect to the latter, perhaps medical students should rotate through a chronic pain clinic in order to learn from the mistakes of those that went before them.

Venturing into the shadow of modern medicine, the stuff we haven't gotten right, and glimpsing the beast in the face is a daunting challenge. Still, this is the beast that these patients live with on a daily basis - an experience that often leads to them to feelings of being persecuted, and even becoming persecutory as a consequence.

## 5.8. CONCLUSIONS

The findings of this research will be briefly summarized as a conclusion.

The pain experience brought a form of the most severe suffering to the patient. Insomnia is a pervasive complaint. Feelings of helplessness and lack of control are a central issue. Isolation and alienation are experienced as a consequence of being in chronic pain. Despair is experienced by all sufferers, as is a dire need for the pain to be witnessed and validated as real. The practitioner managing the chronic pain patients needs to be aware of these common feelings experienced, so that they can recognise, facilitate expression, empathize, and help normalise them. Then a plan of management can be worked out together with the patient to help regain some sense of control. Loss is also a major theme in patients' lives, particularly of a sense of self and financially.

Surgery failed to relieve all patients of pain. The doctors inadequately managed patients' feelings around this failure. Morphine was not found to be as helpful as hoped. Pain management courses are effective and self-coping techniques help. Caution around surgical interventions that have an unpredictable outcome is strongly advised following this research.

These patients felt betrayed and angry with doctors and had experienced a breakdown of trust. Negative feelings towards doctors had not been contained adequately. These patients felt worse off for doctors' interventions. Doctors need help to manage their own feeling when they fail. Patient's expectations of doctors had initially been for a cure. This expectation then shifted to requiring honesty and a knowledge of their own limits from the doctor.

In closing it seems worth noting here, that when discussing chronic non-malignant pain one refers to a group of people suffering from multiple dissimilar problems. This compounded the fact that the acute model of pain is still often used to understand chronic pain. As a biomedical model that undervalues the emotional, social and cultural aspects of illness, it is hardly appropriate. Added to this is the global reality that undergraduate medical training seldom involves rotation through a chronic pain clinic, and a culture amongst medical graduates that failure is not an option. What arises from all this is the complex problem of chronic pain, and the shadow of western medicine, however incompletely understood.

By way of synopsis, a diagrammatic representation of "The cycle of Chronic Pain" is tentatively offered and appears at the conclusion of this chapter. This diagram indicates two separate tracts that may be taken from the initial pain causing insult. The cycle of chronic pain was the one the patients' of this

study were in. As the alternate tract, the cycle of adaptation, suggests (see diagram), a different intervention by the doctor and different choices made by the patient might result less pain. As doctors looking broader and attempting prevention rather than cure by addressing our part in causation is critical.

In another vein the function of unravelling the meaning of our patients' pain is perhaps even more challenging. Seers & Friedl (1996, 1166) state that "talking to patients in chronic pain about the meaning of their pain is crucial, to help in coming to terms with their pain and improving quality of life." To this Morris (1991, 267) adds: "pain is more than only nerve impulses and always requires a personal and cultural encounter with meaning".

Perhaps this then is the crux of the challenge that lies ahead of us as we encounter and minister to those suffering from chronic pain.

### 5.9.1 RECOMMENDATIONS FOR FUTURE RESEARCH

Stemming from this study, a list of ten possible future research topics concludes this report.

1. Do people with poor surgical outcomes develop adverse relationships with their doctors or do certain ways of relating result in poor outcome of surgery? Or are there predictors for poor outcome following back surgery? A psychological assessment would be done prior to surgery and outcome assessed after surgery to see if outcome is related to personality.
2. What predicts good outcome post surgery? A prospective study looking at personality type, relationship with doctor, support structures etc before surgery and assessing that against outcome of surgery with regard to short and long term symptom relief, number of days in hospital, days to mobilisation, etc.
3. To what extent can mutual participation be introduced in managing patients with chronic pain? Could we introduce a training course for a sample of doctors and patients to see if there is any difference between the outcome between the experimental and control group of "untrained" doctors and patients?
4. We need to introduce an assessment of mindfulness-based stress reduction courses as an intervention for patients with chronic pain. Typically, these courses consists of a series of



techniques where people are taught to use simple non-judgemental awareness of the present (painful) moment to attain stress reduction.

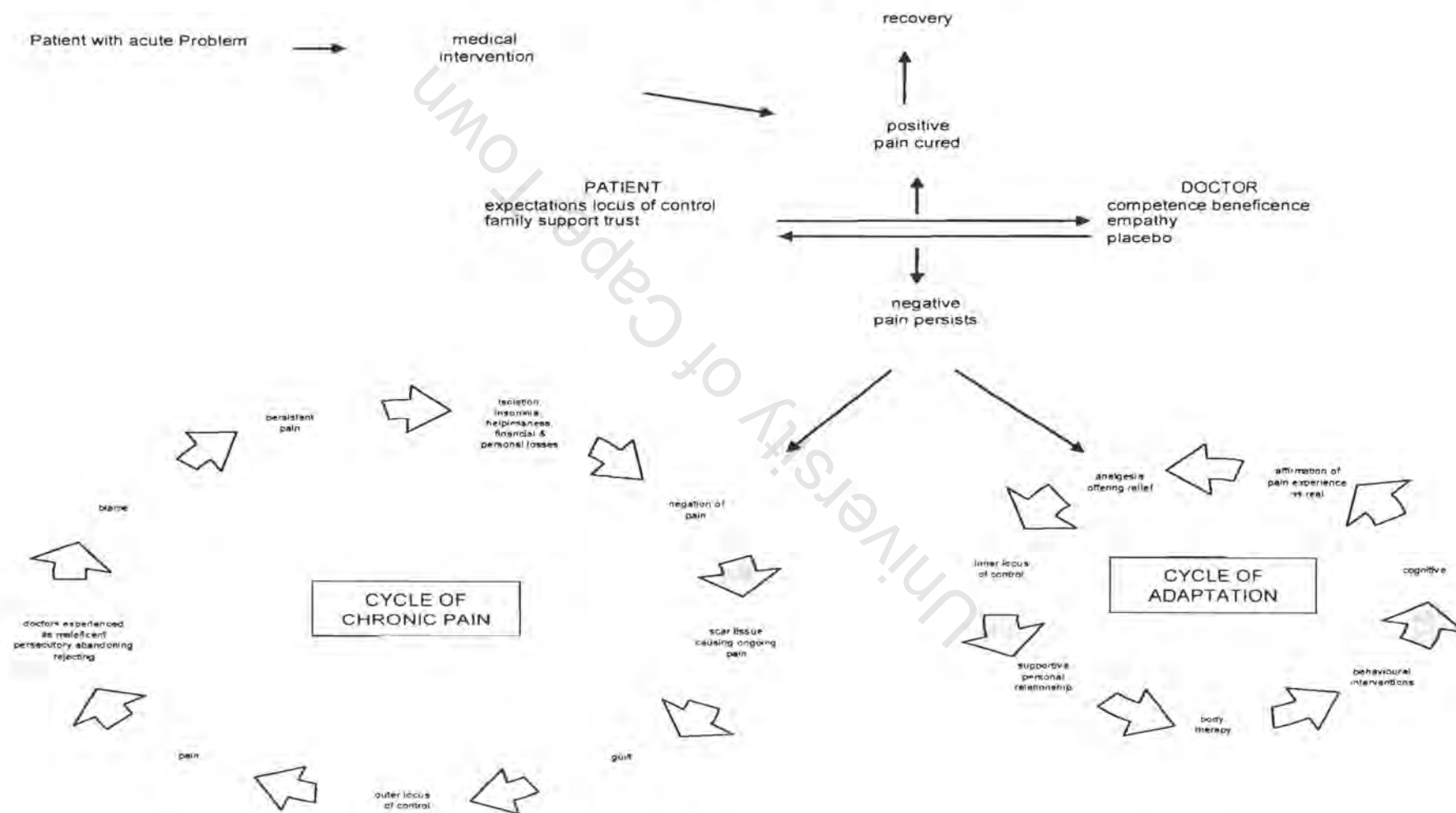
5. Do patients with chronic pain suffer more psychiatric disorders, including personality disorders, than patients without chronic pain? (This research has already been conducted elsewhere).
6. What are doctors' perceptions of patients with chronic pain?
7. What are doctors' perceptions of, and behaviours towards patients who develop chronic pain post surgery?
8. Conduct a descriptive study of doctors and patients meeting after "failed" surgery.
9. What is the impact on the family when a member suffers from chronic pain? Here particular emphasis would be placed on their thoughts, feelings and coping mechanisms.
10. For families where a member suffers with chronic pain, what is the effect of family intervention measured by means of a family functioning rating scale?

### 5.9.2 RECOMMENDATIONS TO IMPROVE CLINICAL PRACTICE

Following this research I recommend: –

1. Use of the patient centred methods of communication. In the context of chronic pain this means specifically allowing the patient space to bring their own agenda to the consultation and negotiating a treatment plan together
2. That surgery is not embarked upon until the patient is ready for such intervention and has thorough knowledge of the risks versus benefits.
3. Doctors hear patients' distress at the failure of their interventions and respond humanely and appropriately both to the patients and to themselves about their failures.
4. Managing chronic pain suffers requires the doctor to both validate the pain as real and facilitate the patient to take control of as much of their lives as possible.

### Diagrammatic representation of the CYCLE OF CHRONIC PAIN



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